**ABSTRACT**

**Background**
People at the end of life have different needs that can only be partly met by formalised health and palliative care resources. This creates the opportunity for the community, the family and the person's social support network to play a crucial role in this stage of life. Compassionate Communities can be the missing piece to a complete care model at the end of life. The main objective of this study is to evaluate the REDCUIDA intervention for the development and management of networks of care around people with advanced disease or at the end of life.

**Method**
A prospective, descriptive and comparative study on a sample of advanced and terminally ill people under palliative care teams supervision with a proxy who have agreed by informed consent to participate in the study. Design: Descriptive study of REDCUIDA intervention and prospective comparative of 2 cohorts; Intervention: Patients and families who are participate in program and Control: Patients and families who do not participate.

6 interventions (one each week) are carried out by the community promoter or healthcare professionals involved in caring. The aim of the interventions is to create or manage networks of care around people through community involvement. An intervention protocol has been created (REDCUIDA) which includes an evaluation of: patient needs for basic and instrumental activities of daily living, accompanying needs, loneliness, quality of life, use of the health system resources, existence of care networks, caregiver burden, and family satisfaction. A baseline analysis of the patient's condition will be established at the beginning of the interventions and compared with the result obtained after 6 weeks of the intervention.

**Discussion**
The results of this study will provide evidence on the benefit of creating and managing networks of compassionate communities that care for and accompany people at the end of life. It will introduce a diversity of processes developed by different types of caregivers that help to develop tools that guide people in completing the activities they can contribute most to, thus creating networks of care in which citizens and organizations share the same objective: to improve end of life care.

**Keywords:** Palliative care – Public Health – Compassionate Community - Social intervention
BACKGROUND

Palliative Care provides a professional, scientific and human response to the needs of those living with advanced disease or facing the end of life, whilst also supporting their families. Experts in this field are organized into multidisciplinary teams to provide a comprehensive care model to address suffering, symptom management and other emotional, social and spiritual aspects associated with the final stage of life, death itself, and the grief of relatives. Palliative care is a type of care that best responds to the needs of these people and their families, in such circumstances and is internationally recognized as a right of citizens. Palliative care can be provided across multiple settings and at it's centre is impeccable assessment. Studies indicate that whilst aiming to be holistic and widespread, palliative care resources cannot possibly cover all patient and family needs. Furthermore, differences in the family structure (smaller family sizes and employment, etc.) mean that some patients made require more social and practical support than others. This is where mobilisation of a person's wider support networks can play a crucial role.

Where a person has strong family support, it is usually, the main family caregiver who recognized as the person involved in the principal care of the person living with advanced illness, often acting as the main point of contact with health and social care professionals. This person may assist with meeting the person's day-to-day physical, social and emotional needs. Outside of the immediate family network, there are other support networks present around a person in need, who can and may assume other necessary tasks. Evidence suggests that up to 7 different profiles of people have been identified that intervene in the caring process of someone facing a terminal illness until the moment of their death. Mobilisation of this wider network is at the heart of health promoting palliative care and the concept of compassionate communities.

Towards a new model of care at the end of life: The involvement of Compassionate Communities

Kellehear's theoretical framework of a compassionate community, that includes the creation and mobilisation of internal and external support networks around a person living with life limiting illness is gathering momentum internationally. This new model of care operating in countries including UK, Ireland, India, Canada, Australia, and Spain brings together not only health and social professionals and primary caregivers but also the wider community (including extended family members, friends, neighbours, volunteers, work colleague) to support people and their families at end of life. At a wider organisational level, the model of care may also include schools, universities, workplaces, companies, the arts community, social care / community development organisations and policy makers. It is intended that through such a model of community intervention, there is an awakening and heightened activity of citizens regarding palliative and compassionate care. Compassionate Communities integrate and promote palliative care socially in the life of people that are creating caring solidary groups, teaching people how to care for people in end of life situations.

Healthcare organizations and policy makers are increasingly involved in the design, development and evaluation of compassionate communities models, recognising that they offer an opportunity to support the reconfiguration of health and social services, reduce costs and facilitate models of integrated care. This means that a focus on community development provides the opportunity for palliative care to progress towards a vision much more closely linked to public health. Such is the case that the World Health Organization (WHO) has included the development of compassionate communities based on awareness, training and implementation of networks in the guide for the planning and implementation of palliative care services.

In setting up compassionate communities, it is clear that, in addition to raising awareness, empowering the society and bringing together organizations involved in care at the end of life, it is considered fundamental to understand the composition of the networks of care within both a community setting and at the individual level. Only then we can build a personalized response to the needs of people at end of life, adapted to the socio-demographic characteristics of a particular region or country. This is seen when citizens or health professionals act with the community to create and manage networks of care and support. There is evidence that shows that the participation of a larger number of community
members at the end of life improves the quality of life of people and their families living with advanced
disease or facing the end of life. Studies also show service and economic impacts, through reduction in
the amount of visits a patient and their relative makes to health and social care services, including
emergency out of hour services.

ALL WITH YOU® [TODOS CONTIGO]

One of the largest and most successful models of Compassionate Communities in the world
began in Seville in Spain. ALL WITH YOU® (a direct translation from the program's Spanish name, Todos
Contigo) is a social innovation programme created by the New Health Foundation in 201419. It seeks to
transform care for people with advanced chronic conditions that require palliative care by monitoring and
optimising healthcare and social services, providing support to families, mobilising community-based
assets, and promoting greater awareness of the challenges and opportunities associated with palliative
care and the management of complex chronic conditions. New Health Foundation enables organizations
through the judicious and systematic application of three inter-related programs known as: NEWPALEX®,
ALL WITH YOU® and iNEWCARE®. Each of three programs complements and strengthens the others,
producing a virtuous cycle that builds in momentum with each joint victory towards radical change, through
the integration of healthcare and social services, and community engagement18. ALL WITH YOU®
programme promotes the development and long-term success of compassionate communities and cities
in Spain and Latin America, involving organizations and the general public in the design and execution of
activities focused on raising awareness, training, research and implementation of care and support
networks for people with advanced disease or who are facing the end of life. The main objective of the
ALL WITH YOU® programme is for people who are living with advanced illness or facing end of life can
satisfy their primary needs through the social and health care services provided by palliative and
community care, together with their networks of support. Within this programme a methodology has been
created (ALL WITH YOU® Method) to facilitate organizations to develop compassionate communities and
cities, supported by a skilled team, and tools. To identify the unmet needs of people with advanced illness
or who are facing end of life and to obtain a deep understanding of the network of people and
organisations involved in providing care as a part of the ALL WITH YOU® programme, the REDCUIDA
intervention has been developed.

REDCUIDA Intervention

REDCUIDA is a compound Spanish term formed by the words “red” (network) and “cuida” (care), which
together mean “Caring network”. Essentially, REDCUIDA is a series of six interventions, used to support
community, health and social care providers, to create and manage networks of care effectively around
people and their families living with advanced illness or at end of life. Central to the REDCUIDA
intervention is a ‘community promoter’ who advocates for and facilitates holistic and integral collaboration
between formal social care and health care providers and professionals.

The ‘community promoter’ position is filled by a person who is:

- Trained and specialises in community development and the social aspect of care;
- Able to be with unfamiliar people who are facing advanced disease and end of life;
- Able to observe and analyse the needs of others, to manage and respond to emotions, and
  emergencies that may arise, as well as to maintain the necessary professional distance.
- Socially skilled and feels comfortable advocating for and asking for the collaboration of different
  members of the community.

The REDCUIDA intervention is delivered over the course of 6 weeks, with a different intervention taking
place each week during a face-to-face meeting between the community promoter and the person living
with advanced illness and/or their family to identify unmet needs and community networks that can satisfy
them. People who are receiving palliative care services are referred to the intervention. An initial (V0)
assessment of their needs is conducted. This first step aims to detect the degree of presence of care and
support networks that can be mobilised during the progression of the disease. At this point, the
beneficiary's referral sheet (APPENDIX 1) and the requirements sheet (APPENDIX 2) are completed by
the community promoter. In the case of requiring more detailed information from the person, a face-to-face
meeting is held with the health professional involved prior to this initial assessment during intervention.

Following V0, the need for the further development of care networks and intervention by the community
promoter will be detected. A meeting between the health professionals, the beneficiary and their family is
arranged to inform them of the plan to create and manage a caring network within their community. First time referrals for beneficiaries entering the program can be made by health professionals, and the community promoter should be notified by telephone.

Those who accept the involvement of the community promoter after the V0 assessment and meeting will receive an invitation letter into subsequent phases of the programme, which includes the creation of care networks. Once accepted, through informed consent, the community promoter will contact the family to arrange the first in-person visit. At this point, interventions for the creation and management of care and support networks are carried out, with the initial visit (V1). This first visit is used to understand the starting point, a baseline analysis for the activities ahead (APPENDIX 2 to APPENDIX 8).

At the end of the interventions, a final evaluation (V7) is conducted to re-evaluate the coverage of needs by the network and to evaluate the satisfaction of family and carers involved. This questionnaire will be administered by phone, by an external professional that has conducted the interventions, in order to avoid information bias in the responses regarding satisfaction with the service. In case of not covering the circle of care within the 6 interventions, patient and family can return with the intervention again to cover their needs (12 interventions in total).

Upon initiation of the protocol, socio-demographic data of the beneficiary and the presence of a support network is collected and completed by the health professionals and community promoter during the baseline assessment (V0).

During the subsequent interventions, several assessments will be conducted, for which it is recommended to use the following scales:

- **Identification of needs related to basic daily living activities**: It is recommended to use the Barthel scale or a validated Spanish version. This scale facilitates the assessment of the autonomy of the person in performing basic and essential activities involved in daily living such as eating, washing, dressing, tidying, moving from the armchair or wheelchair to the bed, going up and down stairs, amongst many other activities. It can be self-administered, evaluated with direct observation or completed by the patient or caregivers (APPENDIX 2).

- **Identification of needs for instrumental daily living activities**: Lawton and Brody’s original scale. This measurement allows the assessment of the person’s ability to perform instrumental activities that are necessary to live independently in the community for example, buying and preparing food, handling money, using the telephone and taking medication. It evaluates more elaborate abilities that tend to be lost before those related to basic activities of daily life. This assessment can be self-administered, directly observed or completed by asking the patient or caregivers (APPENDIX 2).

- **Circle of Care (APPENDIX 3), adapted from Julian Abel's Circles of care**: This resource is used for the identification of care networks in the community that can meet the person’s needs with advanced disease or at the end of life. It can be self-administered or assessed via a direct interview with the patient or their caregivers.

- **Ability to receive help and being satisfied by receiving it**: A variable will be included on the patient’s and family’s ability to receive help upon initiating the intervention and during the subsequent interventions that create the opportunity to identify how the person’s perception can change in general because they have received support from the community. These evaluations are made in person through direct questioning by the promoter to the patient and the patient’s family in the program during each of the interventions that are performed.

- **Identification of social solitude through the ESTE II Scale**: Expanded from the ESTE scale and adapted from Jon Gierveld, this scale is composed of 15 items focused towards the measurement of the perception of social support, the use of new technologies and an index of social participation. It must be administered directly to the patient or by asking the caregiver (APPENDIX 4).

- **Quality of life scale, EUROQOL 5D (EQ-5D-3L)**: This is a generic instrument for measuring the quality of life related to health. It is composed of a descriptive system of their self-assessed state of
health and visual analogue scale (VAS). A third element of the EQ-5D-3L is the index of social values that is obtained for each health state generated by the instrument. The descriptive system contains five dimensions of health (mobility, personal care, daily activities, pain / discomfort and anxiety / depression) and each has three levels of severity (no problems, some problems or moderate problems and serious problems). This assessment is self-administered or completed by directly asking the patient. (APPENDIX 5)

- Zarit scale\textsuperscript{38,39}: This tool is adapted to Spanish\textsuperscript{40} and is used specifically to assess the variable burden of the caregiver in the provision of care to chronic patients. It is performed by directly interviewing the caregiver (APPENDIX 7)

- Satisfaction Scale of relatives or care networks of patients who have been cared for in the community: This has been adapted from Villavicencio\textsuperscript{41} and Molina\textsuperscript{42} (APPENDIX 8), and will be conducted by an external professional via phone call upon completion of the interventions.

During the intervention processes and the creation of networks of care, the community promoter will follow a series of activities based on D. Horsfall's method for the creation of ecosystems of care around people at the end of life\textsuperscript{43}. The interventions that form a part of this method can be summaries as follows:

1. **Compiling information.**

Focus groups and interviews with different groups: main caregiver, informal networks of care and external networks. In this phase various tools can be used that help to compile the most amount of information: photos, maps and diagrams of the circles of care, for example. These methods are particularly useful for helping people open up emotionally and take on potentially sensitive topics that can make them feel vulnerable or exposed, enabling them to approach these ideas more comfortably and making it more personal.

2. **Individual interviews with current and past primary caregivers.**

Individual interviews that address the information provided later with the primary caregivers. These interviews will allow exploring the nature and role of the informal care networks in supporting the person at the end of life and their caregiver and addressing attitudes toward care at the end of life. These interviews can last an average of 1 hour and should be held at the location that the caregiver chooses.

Before drawing the map, it is recommended

Before drawing the map it is advisable to help the caregiver complete a template where the following information is included in columns:\textsuperscript{44}:

- People and animals with whom you live,
- Caregivers (differentiating who the primary caregiver is, and who cares for others,
- People who live with the person they care for (in case they do not live with the person they care for),
- People who also care for the person they are the primary caregiver for (family, friends, medical teams or other professionals should be included here),
- People who care about and support the caregiver (eg, a friend, family member, social group, or someone who provides respite)

To represent people in the map or circle of care, symbols can be used. Lines should be used to communicate the relationship between each person. Different types of arrows can be used to show how often care is provided and the directionality.

3. **Establish focus groups with the identified networks of care.**

To access the identified care networks, primary caregivers can be contacted by phone and email. This exercise explores the role of the network, as well as identifying changes in individuals and networks as a result of caring for others.
This phase is also very useful as a community building activity because it allows the networks to reflect on their experiences in terms of building communities and relationships as well as their attitudes toward death and people at the end of life. The approximate duration of these group sessions is 3 hours and usually takes place in the home of the primary caregiver.

4. **Telephone interviews with the members of the external network.**

The external network is identified in the focus groups and interviews (examples include: teachers, friends of friends, volunteers, people who provide social support to the network of caregivers, etc.). In order to contact this network, the main caregivers and the informal network can be asked to distribute information so that the members can be contacted by those responsible for the project. Interviews with members of the network, given their nature, can be made by telephone. This interview addresses the members’ knowledge about care at the end of life, the knowledge they have about the role they played in connecting with the people most directly involved in the care network and the effects, if any, in the attitudes about death and care at the end of life. At the end of the interview, approximately 30 minutes in duration, the network maps are developed.

5. **Information Analysis**

**Analysis of the interviews (individual and phone) and focus groups:**

Once the individual and focus group interviews are carried out, all the information collected is analyzed. Firstly, the information of the individual interviews with the caregivers is analyzed, examining the reported experiences of the caregivers of having or not having a care network, the perceived differences of having a network, how the networks are mobilized, the attitudes towards death and the end of life and about being part of a network of care.

The analysis of meetings with the informal network and the external network focuses on the following questions: What are the central attitudes about care, death and care at the end of life, and about being part of a network of care? How were these people integrated into the network and what did they do? How does it affect you to be in a network of care?

**Analysis of the network maps:**

The analysis of the network maps is first made at the time of the interviews and the focus groups, noting the assessments given by the participants (exploring the meaning of a component of the network and the map in general for them). The maps are then analyzed to identify the reach, density and strength of the network or identify any significant changes in the network upon tracking it.

### OBJECTIVES

The objective of this study is to evaluate the RECUIDA intervention for the creation and management of networks of care that cover the unmet needs around a person with advanced diseases or at the end of life.

#### Specific Objectives

- Identify the precise nature of a patient’s unmet needs that can be address through mobilisation of the community?
- Detect potential members of the support networks that can meet the identified needs, and describe their fundamental characteristics (caregiver profiles).
- Analyse the influence of the community promoter’s interventions on the emergence and growth of support networks as the disease progresses.
• Assess the influence of this intervention on the quality of life of the patient and on the reduction of the burden on the main caregiver.
• Establish the extent to which this intervention reduces the workload of professionals and the consumption of health and social resources during the process of care at the end of life.
• Analyse the influence of the use of the REDCUIDA intervention with the preference of the place of care and death.

METHOD

Hypothesis

The use of the REDCUIDA protocol in a community intervention program allows the expansion of care networks that can meet the needs and improve the quality of life of patients, increase family satisfaction, reduce the burden on main caregivers, improve the possibilities of care and death in the preferred place and reduce the consumption of healthcare and social care resources during the end of life.

Study design

The study is designed with 2 phases:

1) Descriptive study on the application of the REDCUIDA protocol in the population participating in the Palliative Care Program (PCP) and/or in the ALL WITH YOU® program using the REDCUIDA protocol.

2) A pilot test will be carried out that will allow to identify in advance the willingness to participate in this community intervention program, the sociodemographic characterization of the people included, diagnosis, survival time, covered needs and structure of care networks. This pilot study will allow enable the selection of the control sample for the comparative study.

3) Prospective comparative study of 2 cohorts. The selection of the sample for each of these cohorts will be made by prior decision of the person and family to participate in the ALL WITH YOU® (Todos Contigo) program. Those people who decide not to enter the program will be assigned to the control cohort, being treated in the traditional way by palliative care professionals.

a. Intervention Cohort: patients and families, who are being treated by PC professionals or by social-health professionals specialised in advanced disease care, participating in the ALL WITH YOU® program for community intervention, and are undergoing the REDCUIDA protocol.

b. Control Cohort: Patients and families who are being treated by PC professionals or social-health professionals specialized in the care of advanced illness in a residence, hospital or at home, and who decided not to participate in the ALL WITH YOU® program with the REDUCUIDA protocol.

Beneficiary population

Control Cohort: Persons with advanced oncological or non-cancer diseases at the end-of-life who are being monitored by professionals from palliative care teams or social-healthcare professionals specialized in advanced disease care in the residential, hospital or homecare settings who have not accepted to participate in the ALL WITH YOU community intervention program.

Intervention Cohort: Persons with advanced oncological or non-cancer diseases at the end-of-life who are being monitored by professionals from palliative care teams or social-healthcare professionals specialized in advanced disease care in the residential, hospital or homecare settings and that are a part of the ALL WITH YOU program and participate in the REDCUIDA protocol (see Appendix 1).

Number of beneficiaries

Data will be analysed for the first 100 people who participate in this program.
For a community of 100,000 inhabitants, an estimated 250-400 people per year are likely to have advanced diseases and at the end of life. All those who have been referred to the program and are monitored by palliative care teams can be evaluated.

It is expected that in one year a community promoter may be creating and managing networks of about 100 beneficiaries who are experiencing terminal illness or are at the end of their life (based on data per 100,000 inhabitants / year).

**Variables:**

The variables to be used for the descriptive study on the REDCUIDA Protocol are the following:

- Number of needs according to Barthel and Lawton and Brody Scales
- Patient's and family's ability to receive help and being satisfied by receiving it
- Nº of people who are part of the network of care
- Network caregiver profiles:
  - Relationship to the patient
  - Age
  - Sex
- Number of needs that have been covered by the network.
- Quality of life
- Degree of loneliness
- Burden of the principal caregiver
- Satisfaction of the care network
- Place of death
- Community Promoter Activity Data
  - N of interventions performed at home
  - N of interventions carried out in the community (district, neighbourhood, city, community of neighbours, etc.)

The variables to be used for the comparative study, measurements will be the following:

- Use of the healthcare system:
  - Number of hospital admissions in the last month
  - Days of hospital stays in the last month
  - Number of emergency visits in the last month
  - Number of visits of the palliative care team at home
  - Number of visits of the palliative care team to hospital
  - Number of telephone calls made by the palliative care team

**Data Analysis**

**Descriptive Analysis**

An initial descriptive analysis of the variables related to the needs of the patient and the profiles of people involved by degree of kinship will be carried out.

Subsequently a comparative descriptive analysis of the needs that have been covered by professional and informal caregivers, volunteers, organizations, and any other entity involved in meeting the needs of the person with advanced illness or at the end of life will be carried out. The satisfaction of family members will also be analysed in a descriptive way at the end of the intervention.

Descriptive measures will include measures of central tendency (mean), confidence intervals for the 95% average and contingency tables (frequencies) and a linear regression for each of the variables recorded.
and for each of the assessments conducted during the entirety of the care process until the death of the patient.

**Comparative analysis:**
An analysis will be conducted to understand the effectiveness of the interventions aimed at improving the quality of life of the beneficiary, reducing the burden on the primary caregiver and reducing the consumption of healthcare resources.

For the comparison of proportions, the Pearson test x2 or, where appropriate, the T-Test will be used to calculate the equality of means for independent samples in the case of continuous variables, with a 95% confidence interval.

Statistical software SPSS 15.0 for Windows will be used for all the previously described analyses.

**Sources of information and data collection**
The data will be collected from the patient's own medical history and the information from the REDCUIDA protocol.

The data regarding variables not included in the protocol, such as the use of the healthcare system, will be collected through a direct interview with the patient or caregiver and the principal healthcare professionals regarding the visits in the last month (Annex 6). In addition, the professionals of the palliative care teams will be asked for data on the activity corresponding to the consumption of healthcare resources (before and at the end of the care process) such as: the number of hospitalizations in the last month, the amount of hospital stays, number of visits to the emergency room in the last month and general actions performed by the professionals of the palliative care team.

**Data access and protection**
The community promoter and healthcare professionals will have access to the beneficiary’s clinical information once enrolled in a palliative care program. The permission of the beneficiary and their main caregiver or closest connection shall be required in writing and verbally in order to be able to access the data and use the corresponding data of the interventions for analytical purposes. In order to ensure confidentiality, the identification data of the beneficiary will be coded in order not to have clinical information that identifies them.

The data, without identification of individuals, will be returned to the community promoter and the New Health Foundation for data processing and analysis.

The questionnaires will be coded with an alphanumeric identifier that will be separated into another database independent of the one containing the participant’s identification data.

**Possible limitations of the study**
It is possible that there is heterogeneity in the population depending on the complexity of each of the beneficiaries and the profile of needs that they may require. To mitigate this effect, homogeneity tests of the population under study will be made.

Although it is not the purposed use for this protocol, there are other clinical variables that influence the needs of the patient such as the complexity and the consumption of resources that also influence the network of caregivers. These variables have been taken into account since they are recorded in the patient's medical history and will be taken into account for future studies within this line of research.

**Ethical considerations of the study**
During the implementation of the interventions and taking into account that it is mostly an observational study, the methods consider, at all times, that with the judgment of the healthcare professionals themselves and the insights obtained from the research are developed with the aim of guaranteeing the respect of privacy, dignity and decision-making of the patient and their relatives.
Throughout the evaluation process with patients and family members, the right to guarantee data protection will be fulfilled. The study must have informed consent sheets on the description of the protocol and will be submitted to an ethics and research committee for its evaluation and acceptance.
DISCUSSION

Identifying the needs of people with advanced disease or at the end of life and those involved during the process are geared towards creating a network of compassionate communities that carrying out a series of caring tasks that up until now had not been identified and are fundamental to cover all aspects of care, beyond the specialized services in palliative care.

The network of care and accompaniment around people from the community facilitates the provision of integrated care centred on the person at the end of life. In addition, knowing how the community behaves in terms of the needs of people at the end of life, will help citizens to appreciate how to care for and accompany those in need, providing tools and guiding through the activities central to creating a network of care where citizens share the same goal: improving care at the end of life.

A multi-centred approach can be used with this protocol to uncover networks of care in other countries within the ALL WITH YOU project.

The results will stimulate the design of a series of services of care and the satisfaction of needs, that are designated and appropriate to the various profiles of carers, professional and non-professional (informal) carers for patients with advanced diseases and at the end of life. In addition, it will serve to identify skills which our population and the next generations, (children, youngers, etc.) should be trained to be able to better take care of the needs of their elders.


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