“Perceived effects of a home-based social care programme on palliative care in Spain from the caregivers' perspective”

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Perceived effects of a home-based social care programme on palliative care in Spain from the caregivers' perspective

This study explores the perceived effects of a home-based end-of-life social care program in palliative care in Spain, from the perspective of caregivers. A qualitative study using semi-structured interviews with 75 caregivers from the INTecum project. Non-probability purposive sampling was used to recruit the study participants. The analytical process followed a thematic analysis. Caregivers expressed several factors that were influential in reducing stress and anxiety. Knowing that they can count on a case manager in a situation of need was highlighted as very positive. Another important factor that helped to create a positive sense of security was the speed of the project in offering its services. One of the problems that arose was the lack of support in situations where a transition between home and hospital care was required. Aspects such as listening and kindness, and affection, are highlighted in a very positive way. In addition to the final desires, caregivers also recognized that it was important for professionals to take their relative's wishes into account when making decisions. Incorporating a psychosocial component in palliative care for both patients and family caregivers is recognized and such actions are recommended, as well the strengthening of social and health care coordination.

Keywords: Palliative care, home-based care, caregiver, end of life, psychosocial intervention, Spain.

Introduction

The need for social and health care in palliative cases has led to the development of social home care programs in recent years. These home-based palliative care programs are provided by a multidisciplinary team to meet physical, psychological, spiritual, and social needs (Kahveci, Koç and Aksakal, 2020). Their main objective is to improve the quality of life of patients and caregivers in the family and community environment, avoiding hospitalization (WHO, 2014, 2020; Dhiliwal and Muckaden, 2015). Social home care aims to cover needs related to basic activities of daily living, adaptation of the environment, promotion of personal autonomy, companionship, spiritual expression, leisure and entertainment, and support for caregivers and the social support network (Millas et al., 2015).

Through home-based social and health care services, patients have shown improved quality of life outcomes (Arias-Casais et al., 2020; Thayyil and Cherumanalil, 2012; McKeown et al., 2010; Finlay et al., 2002); decreased use of hospital services (Totten et al., 2016; Lacampa et al, 2009; Gomez-Batiste, Tuca, Corrales, 2006; Dhiliwal and Muckaden, 2015; Millas et al., 2015; Wong et al., 2013) and increased patient and family satisfaction with the service (Norinder et al. 2021; Millas et al., 2015; Clemmer, Ward-Griffin, Forbes, 2008). A body of research has shown the important role of social home care services in improving perceived quality of life and reducing anxiety and stress for patients and carers (Larkin, Henwood, Milne, 2018; Thomas et al., 2016; Lopez-Hartmann, Wens, Verhoeven and Remmen, 2012; Bausewein et al., 2012; Meier, 2011).

It is estimated that, without integrated home-based services, relatives provide from 80% to 90% of care (Millás et al., 2015). This home-based care leads to caregiving overload for family members that is associated with a range of psychosocial problems (Ferrell et al., 2018; McIlfatrick et al., 2018; Reigida et al., 2015; Sklenarova et al., 2015; Harding et al., 2012; Friðriksdóttir et al., 2011). Those providing care at the end of life face quasi-medical caregiving tasks in addition to providing many hours per week with few formal support services (Stewart & MacIntyre, 2013; Vassilev, Rogers, & Blickem, 2013). For this reason, such overwhelming home-based care for family members is associated with a loss of quality of life, psychological morbidity (stress, anxiety, and depression) and social isolation (Gotze et al., 2018; Millas et al., 2015; Herrera et al., 2013). From a gender perspective, the main profile of the caregiver is the wife, daughter, or sister, reporting higher levels of stress and anxiety (Pinquart and Sörensen, 2011).

In Spain, the Law for the Promotion of Personal Autonomy and Care for Dependent Persons, passed in 2006, has not been sufficient to cover the social and health care needs of dependent persons and their families. For example, the study by Millas et al. (2015) shows that only 4.3% of families received public aid for the dependency of patients in palliative care, bearing in mind that 75% of patients had severe/moderate dependency. According to the authors of that research, the time that elapses between applying for care and the assessing dependency and receiving aid in the form of economic benefits and services means that many families do not have the necessary resources in this final phase. In this sense, social care programs in palliative care can be an important resource for the support and respite of caregivers, while promoting permanence in the home and community context and reducing stress in families. As stated by Herrera et al. (2013), it would be desirable to promote and anticipate an integrated health and social care model in the community context due to current socio-demographic trends regarding the prevalence of chronic diseases and the lack of family caregivers at home.

Most research related to the impact of caregiving has been collected using quantitative methods or assessment tools that sought to collect objective indicators of impact. However, the literature review by Larkin, Henwood and Milne (2018) has pointed out that the omission of the subjective perspective of caregivers is a methodological weakness that contributes to an incomplete understanding of the impact of care. Therefore, while there is limited evidence of the effectiveness and cost-effectiveness of interventions, there is a need for qualitative evidence, from the caregivers' point of view, of the perceived benefits of home-based social care (Seipp et al., 2021; Larkin, Henwood, Milne, 2018). The purpose of this study was to find out the perceived effects of a social home care project in palliative care in the Castile and Leon region of Spain, from the perspective of caregivers.

Methods

Design and context of the study

This study uses a qualitative design that is interpretive and exploratory in nature to understand perceptions, experiences, and meanings (Creswell, 2017). At the same time, qualitative research design has been considered as appropriate for research in health and social care services (Neergand et al., 2009) as it accounts for the organizational contexts of care (Buseto, Wick and Gumbinger, 2020). The study presented here is part of a larger evaluative research study that used a mixed-method design to inform the process evaluation of a pilot project in social home care in palliative care in Castile and Leon, from the perspective of patients, caregivers, healthcare social workers and health professionals.

In the Autonomous Community of Castile and Leon, on the initiative of the Social Services Department, a project called INTecum is being developed with the aim of providing comprehensive care for people at the end of life and for their families, with the collaboration of the health and social services system (Table 1). The initiative represents an innovative experience in comprehensive social and health care led by social services with the additional involvement of different administrations (regional and local). The initiative, which was implemented as a pilot project between 2019 and 2021 in the city and province of Palencia, is currently being extended to the whole of the Autonomous Community. The project assumes the model of comprehensive and person-centered care in the field of end-of-life care (Librada, Herrera, and Pastrana, 2015). To this end, it provides care for people and their families going through the end-of-life process by means of a coordinated and rapid response that includes resources from the health and social services. The ultimate goal is to enable people included in the Integrated Palliative Care Process of Castile and Leon to remain in their community context until, if they wish, they can die in their own home.

Insert Table 1 here

Participants and sampling

The data for this study include semi-structured interviews with 75 caregivers from the INTecum project. A non-probability purposive sampling was used to recruit participants for the study. This sampling was applied to all people accessing the INTecum project during its first year of implementation in the province of Palencia. In the vast majority of cases (86.4%), the carer and the person being cared for lived in the same family home. The size of the households, with an average of 2.6 people per household, including the person receiving care, can be considered average in general terms, if we take into account that, according to data from the Spanish National Statistics Institute, the average size of households in Spain in 2019 was 2.5 people. The importance of families in the care and attention of people participating in INTecum is considerable: children and spouses tend to act as main caregivers in practically the same proportion of cases (37.5% and 36.4%, respectively).

In this study, a very significant part of the informal support from the family group to people at the end of their lives is provided by women (71%). According to the place of residence, a large number (39.8%) resided in the city of Palencia, the provincial capital. Bearing in mind that the city currently concentrates 48.7% of the total population of the province, there was a significant presence of population located in rural areas among those benefiting from project.

Data collection

The research team met with the case managers and those responsible for the management of the INTecum project at the San Cebrián Foundation (Spanish anacronym: FSC) to establish the recruitment method and facilitate the home interviews. The FSC case managers contacted the eligible caregivers to ascertain their availability and suitability (depending on the patient's situation) for the interview and to agree on a date. Once the research team had confirmed the interviews, they contacted the program participants to introduce themselves and remind them of the interview date. The interviews were conducted in their homes in order to make the atmosphere as comfortable and relaxed as possible. If the patient's conditions allowed it, the interview was conducted with the patient and the caregiver. All the authors of this study conducted the interviews given their experience in qualitative research. During the research, due to the unforeseen circumstance of COVID-19, program participants were offered the opportunity to conduct the interviews by telephone. Data collection took place between February 2019 and May 2021 throughout the province of Palencia.

A semi-structured interview script was used to conduct the interviews. The script included six sections. The first section explored satisfaction with the information received from the project. Section 2 focused on the support products, personal services and architectural adaptations provided in the home. Section 3 asked about the professional care received from the case manager and, where appropriate, the personal assistant. Section 4 explored the fulfilment of initial expectations and overall satisfaction with their participation in the project. Section 5 asked about the care received from health and basic social services. Finally, section 6 addressed the care received, if any, after the death of the person cared for. This interview structure was consistently used in all interviews, leaving a margin for flexibility, and sounding out emerging themes. The interviews lasted between 20 minutes and 60 minutes, enabling in-depth conversations about the experience and assessment of the services provided in the program.

Data analysis

All interviews were recorded and transcribed by members of the research team and imported into the Atlas.ti 9 qualitative analysis software. Once the interviews were transcribed and imported into the software, the analytical process followed the six phases proposed by Braun and Clarke (2006). Data saturation was achieved when no new themes emerged. Reliability was established throughout the process, in which all team members participated in refining the coding by reading several drafts of the results reports. Any discrepancies in the codes were resolved through consensus in research team meetings (Syed and Nelson, 2015).

Ethical considerations

All participants took part voluntarily in this study and provided informed consent prior to the interview. The research team guaranteed anonymity and confidentiality in accordance with data protection regulations (Spanish Organic Law 3/2018). The research team stored all personal information in a secure database, hosted on the servers of the University of Valladolid, and real names were replaced by a coding system. This research was approved through an agreement established between the University of Valladolid and the Social Services Management of Castilla y León of the Regional Ministry for the Family and Equal Opportunities of the Junta de Castilla y León, the regional authority.

Results

The analysis generated a set of 3 thematic categories and 7 subcategories. Table 2 shows the thematic organization of the results regarding the assessment of palliative care at the end of life. The first thematic category describes the need to ensure continuity of care for the persons receiving care and their family caregivers. The second thematic category focuses on describing the perceived needs of the caregiver. Finally, the last thematic category describes the importance of self-determination in terms of respect for final wishes and autonomy in decision-making.

Insert Table 2 here

Need for continuity of care

Feeling of security in the home care

Respondents expressed several factors that had a positive influence on developing a feeling or perception of security in home care. Having a responsible organization providing qualified staff available at any time was very important for the caregivers' peace of mind.

> And that's another thing: who are you bringing into your house? And this way you go with a certainty that you know that the person is supported and you know that they are qualified. You knew that if you had to go out shopping and the personal assistant stayed, then you knew that they were a responsible person. And that they

> would call you and ask you if you were happy with the assistant because if I wasn't, they would tell me that they could put someone else in. And that gives you a lot of peace of mind. (PC 93)
>
> We are very happy with the project because they have taken care of [the patient] in the last phase of life and especially the issue of the night because it was something we were worried about so that my mother wouldn't be frightened. (PC 02)

Another important factor that helped to generate a positive sense of security was the availability of home adaptations and the provision of technical aids needed by the person to promote autonomy and self-care. In the interviews carried out, the importance of functionally adapting the home was repeatedly pointed out.

> Being able to have my mother at home with everything we had... It was a great help! For example, without the [articulated] bed, moving my mother would not have been possible. I am the youngest male: the youngest of my sisters is 60 and the eldest is 70. For my eldest sister to move my mother without that bed would have been very difficult. (PC 72)

Finally, another important factor that helped to generate a positive sense of security and reassurance among caregivers was the project's speed in offering its services. The short time between the assessment of the situation and the implementation of services by INTecum was highly valued in comparison to other public care services that are perceived as being provided and delivered more slowly. The following quotes allude to the speed of the project.

> They went out of their way so much because we didn't have articulated beds here. And at the same time, they brought a device to wash her head in bed. Very good, very good, a few details and it was done in minutes because they said at such-and-such a time we can have it here..." (PC 02)
>
> It's clear to me, the attention, the speed of the support. That you talk to someone and in a few hours or the next day you have them here... that's efficiency. In the end, what you remember is the fact that they have helped you in everything and very quickly. That when you needed things, you had them. (PC 56)

This sense of security meant that caregivers experienced reduced anxiety, stress or worry.

> I felt very cared for. And all the built-up tension at that time was released. The truth is that they helped me a lot, I was able to channel my anguish. And the thing is that, before you have the need, they solve it and that takes away a lot of anxiety. For me, that's the best thing: reducing anxiety." (PC 75)
>
> The fact of having a person who is going to take care of your family member, I can disconnect. I know that they are not left alone, I know that they are looked after, I know that they are with a person who not only keeps them company, but who is

> helping them with whatever they need. The project frees you up a lot. It's a lot when you have a burden like looking after a person. (PC 13)

Transitions in the care given

One of the problems that came up repeatedly in the interviews was the lack of support in situations where a transition between home and hospital care was required, especially in emergency situations and more seriously at weekends, causing considerable stress and anxiety for the caregivers. The following verbal extracts are an example of this need:

> At weekends there is no one you can count on. There could be something, like someone "on call" and you can call a phone number or call the case manager who will contact the person on call that weekend. (PC 27)
>
> It makes us, the relatives, worried. Because you see that she is nervous, that... you see that she is not herself... that she is not the person she usually is and that she is suffering and you have to calm her down a bit, stop her. And the problem is that you have no response from anyone at the weekends. (PC 02).

Psychosocial needs of the caregiver

Feeling accompanied

The need for qualified professionals to provide technical support is important in reducing stress for carers. However, during the interviews, more than technical support, the humanization of the care provided was highly valued. Knowing that you can count on a known contact in case of need was highlighted in multiple interviews as a very positive aspect. The availability of the case managers at all times is something that is clearly reflected in the following quotes.

> I think it is essential that there is a someone to talk to [case manager]. If you have any issue, you call her and she is there. And it is important because she is the person who takes on the coordination of everything that happens to [the patient] and furthermore she is familiar to the person. (PC 31)
>
> They are very attentive to what I need too. If they have to stay five minutes longer, they don't mind. My husband tells them: ‘come on, it's time, you have to go’. But if they have to stay five minutes longer, they don't mind being with us. That's what I would highlight most (PC 21)

Aspects such as the way people are treated, the kindness, interpersonal relationships and affection are highlighted in a positive way. The following verbal extracts speak of the importance of these professional qualities, as well as having professionals who convey peace of mind in this difficult period for families.

> When you talk to them, they reassure you... the tone of voice, "well, everything's OK, don't worry, little by little" reassures you, even if you are very concerned (...); that reassures me a lot and makes me trust them. (PC 25)
> The best thing was meeting this wonderful person that I met while my wife was ill. I would like to highlight the closeness, that they gave you a hand and took away a lot of anguish. The people in the project gave life to my wife, they cheered her up... For this service you need people you can trust. (PC 71)

On the other hand, in addition to the professional qualities outlined above, having the opportunity to share concerns and feel listened to by professionals was viewed very positively, as expressed in the following verbal extracts from several interviews.

> For me it has been very good because they listened to what I asked for, they gave me what I wanted... Because if you need help with an illness like this and they take care of you like they did, that is priceless. (PC 62)

> And also that you feel listened to. That you feel... I was going to say valued... but you do also feel valued. And sometimes you just let off steam because you don't want to worry your family and then... For example, maybe [the case manager] had come for half an hour and she has spent more than an hour listening to me. (PC 27)

Respite support

The respondents particularly value the benefit of participating in the project because they consider it to have had acted as a means of relief with regard to the burden of the situation of the terminally ill person and the overload for the caregiver. The following comments illustrate the respite function:

> I work, so I can't devote myself exclusively to being there all the time. And knowing that you have a person who is looking after your mother. That she lacks nothing. That she is always accompanied. That whatever happens, she is taken care of. (PC 38)

> Knowing that someone is going to come and help you and that if you want to go for a walk... you can go out... They are doing marvelous things. (PC 44)

Balance between intimacy and care in the home

Another perceived barrier is the need for a certain balance between maintaining privacy and adequate home care. Respondents want to live their lives as normally as possible in their own homes without a perceived sense of "intrusion" or "invasion" by outsiders. Most of them expressed the need that when personal assistance services are offered, every effort should be made to ensure that only one person comes to the home.

> There was a day when the girl who comes in the afternoons couldn't come in the morning because she was somewhere else and couldn't come. So [the manager] sent me another girl, but of course then two different people come to the house... what happens? Well, the children already see two different people and then comes the problem that the children choose, they prefer that one comes more than the

> other... That's the bad thing. Of course, I think that the same one should always come, that it should always be the same one. (PC 27)
> And we preferred not to have a different person come just to cover the Saturday afternoon. Why? Because privacy is important. It's one thing to be assisted, and it's another thing to feel invaded. And look, we have been offered more help, but no, not a different person, because we don't need this back and forth of people in the house. It is very important not to have different people every day. (PC 31).

Need for self-determination

Respect for final wishes

The most repeated reason for the preference to die at home was that it was the cared-for person's wish to be at home at the end of life. This wish was important for the caregivers as they wanted to fulfil their relative's last wishes. The following excerpts reflect the positive assessment of respecting those final wishes.

> It was what we wanted and, above all, it was what she wanted. She didn't want to go to the home even if she was dragged. She asked me: What are you going to do with me? Because she was aware of everything; she had a good mind until the last moment... And I answered her: 'We're going to throw you out of the window'. She stared at me... 'No. We're going to take care of you the best we can, as far as we know, at home.' (PC 17)

> Yes, we wanted my mother to be here with us. Because we knew she was not going to last long and however long it took, we wanted her to be with us. Because she always wanted to die at home. She always said, 'in her little house'. She was very happy here with me and my sister. And I was very grateful. (PC 73)

Autonomy in decision making

Together with the final wish, carers also recognized the importance of professionals taking their own desires into account when making decisions. Knowing that their opinions and preferences were borne in mind meant more peace of mind and satisfaction with the care given to the carers. The establishment of a collaborative atmosphere was rated very positively.

> The palliative home support came very often and when we saw that the situation was irreversible, there was the person who was her personal assistant and there was also a doctor, the nurse, and a psychologist, and there together we decided whether to take her to the palliative [hospital] to spend her last hours or to do it here at home. And I felt very supported and they made everything very easy for me. What's more, it was her wish to stay at home. (PC 54)

> I should take her home [was the suggestion in the emergency room] I wouldn't keep her here because... for her and for you it will be better if you have her at home, but it's your decision. And we brought her home. (PC 3)

Discussion

This qualitative study was designed in order to understand the perceived effects of piloting a home-based palliative social care program in the Spanish region of Castile and Leon, from the perspective of the family member caring for an ill person at the end of life.

The results of our study show that palliative care at the end of life leads to anxiety, stress, and caregiving overload, negatively affecting caregivers. In this sense, participation in the INTecum project improved perceived quality of life and reduced anxiety and stress in caregivers, as illustrated by most of the verbatim interview extracts shown in the results section. These findings are similar to previous studies that have shown the important role of home-based social care in improving perceived quality of life and reducing anxiety and stress for caregivers (Norinder et al. 2021; Norinder, Goliath, & Alvariza, 2017; Millas et al., 2015; Herrera et al., 2013). The study by Alvariza et al. (2017) is revealing because it shows how the absence of a psychosocial component in the PREFER program, a palliative homecare program developed in Sweden, did not help to meet the need for support and accompaniment of family members in their role as caregivers. Alvariza et al. recommend the need to incorporate a psychosocial component in palliative care aimed at both patients and family caregivers. These results are in line with the support theory developed by Öhlen et al. (2007). This theory states that providing reassurance to family members is an affirmation that the patient is experiencing as far as possible a good quality of life, benefiting the quality of life of family members and the domestic context.

At the same time, our results point to the importance of designing interventions shaped by the person cared for and the family caregiver, recognizing the fact that terminal illness is experienced as a dual unit of care. This aspect is important in the palliative care setting, as the care is inevitably centered on both the person at the end of life and the caregiver. Previous studies examining the effect of interventions that take the patient-caregiver dyad as a unit of care have shown that they improve patient support and prevent negative health outcomes for caregivers such as symptoms of anxiety, distress, or depression (Hermosilla-Ávila, Sanhueza-Alvarado and Chaparro-Díaz, 2021; von Heymann-Horan et al., 2018a, 2018b; El-Jawahri et al., 2017; Dionne-Odom et al., 2016, 2015). Designing interventions from a dyadic perspective entails assessing the existing interaction in the family, its communication patterns, the way in which this family core relates to the community in which it is inserted, its beliefs, its expectations, its potential and the aspects that hinder the achievement of goals (Agrafojo, 2016). In this sense, our study shows the importance of dyadic psychosocial support interventions. For example, the randomized controlled trial conducted in Denmark evaluated dyadic social support intervention to terminal-stage cancer patients and their informal caregivers within the framework of a home care program called Domus (von Heymann-Horan et al., 2018a). Their results show that dyadic psychosocial intervention alleviated increased anxiety and depression.

There is a line of research focused on communication between professionals and patients with advanced illness and family members that has identified that poor communication has a negative impact on the quality and continuity of care (Glenny et al., 2013). To develop social interventions, through home care palliative programs, it is essential to explore the quality of communication to reduce negative effects on patients and caregivers such as anxiety or stress. Our findings show that accompanying the caregiver by informing, communicating, supporting them emotionally, ensuring that they are listened to, can participate in decisions, receive clear and honest answers, and can express their emotions, are fundamental care processes in palliative care at the end of life. In this sense, our results show that the case management model in palliative care is beneficial.

Case management is a means of ensuring continuity of care for patients and family members who require complex social and health care (Sepúlveda et al., 2002). Our results are in line with this intervention model because the case manager initiated contact with the patient-caregiver dyad at the beginning of the program and maintained this contact throughout the program, providing accompaniment with sufficient flexibility to respond to the care needs of the patient-caregiver dyad. We believe that the model of accompaniment and flexibility in care planning for healthcare social workers through the case manager is fundamental in order to focus on the development of different needs. The majority of caregivers in our study positively valued having an immediate response to their needs as soon as they arose, revealing the importance of the flexibility of this model in palliative care. The method of caregiving based on flexibility in addressing needs has been highlighted in the study of the Domus program in Denmark (von Heymann-Horan et al., 2018b).

Support for caregivers by professionals is of great importance to generate a feeling of security and peace of mind (Barlund, André, Sand, & Brenne, 2021; Sarmento, Gysels, Higginson, & Gomes, 2017; Goldschmidt et al., 2006). In this sense, our study shows the great importance of accompaniment as an intervention methodology for healthcare social workers. Accompaniment as a methodology for social intervention allows professional action to be oriented towards processes of change, in both the person and the environment (Raya and Caparrós, 2014). As can be seen in the results of our research, the more caregivers felt that they were listened to and guided and that they could quickly count on a professional to attend to them, the less anxiety and stress they perceived. It is worth highlighting as fundamental aspects of the social intervention of this program, the figures of the case manager and the personal assistant who applied the methodology of accompaniment as a way of understanding the relationship between professional and cared-for person, in a horizontal relationship, where the professional is placed in a position to give help, guidance and support.

Transitions in care have been identified as a perceived threat to patient and caregiver security. The study identified problems in care coordination or lack of communication at weekends or in emergency situations and subsequent transfer to the emergency department or hospital. This area requires attention to reduce anxiety and stress for the patient and caregiver. Transition of care has been recognized in previous studies as leading to fragmented care, causing negative outcomes (Killackey et al., 2020; Coleman and Boult, 2003; Coleman, 2003; Coleman et al., 2004; Foster et al., 2004). According to the WHO (2018), the concept of transition of care refers to a process of care based on continuity of care and coordination, calling for the transformation of health services, which have been designed to date around pathologies rather than services for the individual needs of people.

Regarding the strengths of our research, we note that there are few qualitative studies that explore the effects of a psychosocial intervention in palliative care at the end of life from the perspective of caregivers. Our work is consistent with the recommendation put forward by Larkin, Henwood and Milne (2018) in their literature review on care-related research to take into account the subjective perspective of patients and caregivers in order to assess their well-being and evaluate the impact of interventions. New paradigms of intervention, including the person-centered model, advocate keeping people at the end of life and their families as the focus of all interventions (von Heymann-Horan et al., 2018a). Paradoxically, however, studies so far indicate that end-of-life care often depends on the attitudes of the medical staff or the treatment team, without having much to do with what the person at the end of life and their family want or would have wanted (Zunzunegui, 2018). Another aspect to point out is the contribution of our study to palliative care for the rural population. In circumstances of living alone, very frequent in rural Spain, but also typical of urban contexts, a project such as INTecum can be of particular relevance for the provision of appropriate care in the last moments of people's lives. As for the limitations of the study, the generality of the results is limited because of the descriptive nature of this research and the use of non-probabilistic sampling, which may generate certain bias. For example, it would be interesting to incorporate migrant populations or ethnocultural groups in our region of study.

Conclusion

This study has shown the important role of home-based social care in improving perceived quality of life and reducing anxiety and stress for caregivers. The importance of designing interventions aimed at the cared-for person and the family member providing care as a dual unit of care should be considered in any palliative care project. It is also important to have a person of reference at all times, such as a case manager. Accompanying the caregiver by informing, communicating, supporting emotionally, and ensuring that they are listened to and can participate in decisions, should be fundamental care processes in palliative care at the end of life. The case management model and the companionship model, together with flexibility in care planning through the case manager, is fundamental in addressing the development of different needs. Therefore, the need to incorporate a psychosocial component in palliative care for both patients and family caregivers is recommended.

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Declaration of interest statement

The authors report there are no competing interests to declare.

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Table 1. Description of the key actions in the INTecum project

Key activity	Contents
Caring for the person	Provide health and social care with sufficient intensity so that the person can stay at home, maintaining, as far as possible, their way of life. Provide emotional and spiritual support to help the person face deterioration linked to the development of their illness.
Support for caregivers	Provide caregivers with sufficient knowledge to cope with caring and the emotional aspects linked to the development of the illness. Provide integrated care for the caregiver, offering them rest periods, working on co-responsibility with other carers, fostering the creation of caregiver groups, accompanying them in the bereavement process, etc.
Adaptation of the home	Facilitate the home adaptations and technical aids required by the person in order to promote their autonomy and self care.
Health and social coordination	Act by means of a proactively integrated health and social process, from the moment of inclusion of the terminally ill person into the Integrated Palliative Care Process, providing the support needed for the person to remain at the home they choose with guarantees of quality and security.
Person-centered planning	Development of their life project up to the end.

Source: The authors, taken from the INTecum Project.

Table 2. Summary of the thematic categories and subcategories

Need for continuity of care
- Feeling of security in the home care.
- Transitions in the care given

Psychosocial needs of the caregiver
- Feeling accompanied
- Respite support
- Balance between intimacy and care in the home

Need for self-determination
- Respect for final wishes
- Autonomy in decision making