"Social Work at the end of life: humanisation of the process"

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Introduction

The increase in life expectancy in most advanced societies in recent decades has led to an increase in the number of people with oncological and chronic degenerative diseases who need or will need palliative care in the years to come. This scenario is posing notable challenges from a public policy point of view. On the one hand, it has strained the health and social structures of welfare systems, calling into question their organisation, efficacy and sustainability (Garralda et al., 2016; Radbruch & Payne, 2009). On the other hand, it has stimulated a growing and unmet demand for coordinated care by the health and social care system (Lynch et al., 2013; WHO, 2020): in Spain, for example, the rate of palliative care services is below that for Europe and far from the optimum recommended by the European Association for Palliative Care (Arias-Casais et al., 2019).

At the same time, in recent years there has been a redefinition of the way in which people at the end of life are understood and cared for, inspired, among others, by the pioneering work in the origins of palliative care developed by social worker, doctor and nurse C. Saunders (Buckley, 2008). This new vision implies three relevant issues: care should not be restricted to the last days of life, but should be offered progressively as a disease progresses and according to the needs of patients and families; support should be integrated into the person's community environment and within the framework of their social networks, so that the centre of gravity of the care process should shift from the hospital centre to the home context; care must be comprehensive, responding to the physical, psychological, emotional, spiritual and, especially, social needs of the terminally ill patient and his or her family (Centeno, 2014).

The social needs and problems present at the end of life and the speed with which they arise explain the extraordinary vulnerability of ill people and their carers (Millas Ros et al., 2013). Both have to cope, in one way or another, with economic (meeting the cost of technical aids or home adaptations), emotional (receiving information about the diagnosis and prognosis of the illness, making decisions regarding last wishes), practical (learning to provide particular care), and other highly demanding requirements which have a significant effect in terms of psychosocial discomfort and emotional repercussions (Carolan et al., 2015).

These circumstances are often compounded by others that increase the person's fragility (Gehlert & Moro, 2011); some are of a personal nature (e.g. intellectual disabilities, mental health issues); others involve the person's social networks (including social isolation or unwanted loneliness, problems arising from non-standardised family living arrangements or situations in which family carers give up); and others concern socio-economic circumstances (lack or inadequacy of housing, poverty or social exclusion, etc.). Furthermore, caregivers sometimes do not have the material, social and emotional resources required to accompany and support them in this process or are overwhelmed by the wide variety of highly stressful activities and responsibilities involved (Bermejo Higuera et al., 2014).

As M. Payne (2017) has pointed out, social work and health care approaches overlap: health problems increase patients' frailty and affect their relationships and daily lives, and, similarly, relational problems and a poor quality of life impact on people's ability to cope with illness. Despite growing evidence regarding the importance of the social and relational aspects of end of life care (Osman et al., 2018), such care remains constrained by a predominantly biomedical culture and framed within the parameters of social and healthcare organisation (Perkins, 2016). Proof of this is that comprehensive and multidisciplinary attention through the provision of palliative care is still very insufficient: in Spain, of a total of 2711 professionals dedicated to palliative care, only 7.6% are social workers and 8.9% are psychologists, while 54.1% are nurses and 29.5% are doctors (SECPAL, 2016). These data, furthermore, do not take into account that the commitment of these social workers is, in many cases, shared with other social and healthcare services (SECPAL, 2015) and it is very often oriented towards management and bureaucratic tasks.

However, social work professionals are called to take on particular relevance in end of life care insofar as they take on functions and tasks in the teams in charge of end of life care that are difficult for healthcare staff to carry out (Antifaeff, 2019). Their tasks can be very varied (AECC & CGTS, 2017; Novellas Aguirre, 2017; Vanzini, 2010): social assessment of the family situation, detection of socio-cultural risk factors and preparation of an intervention plan; advice on the management of social resources; mediation in family conflicts and difficulties arising from decision-making; coordination and promotion of volunteer support; advice, training and support for caregivers and families; emotional support for patients and families; and care in the grieving process.

This article explores the relevance of social end of life care in the home setting, analysing the competences of social work in this field and identifying the qualities of social workers most valued by the people who receive their care. The research carried out addressed these issues by giving a voice to social work professionals, health personnel and ill people and carers.

Methodology

Research on issues related to social intervention should, ideally, obtain significant and relevant results to improve services and knowledge for professional action. With this twofold aim, based on the research work carried out within the framework of the evaluation of an innovative initiative for end of life home care (*Proyecto INTecum*), we propose to contribute to knowledge on social and health services for end of life care and, in particular, on the functions and tasks carried out by social work professionals in this field.

Research context.

Located in the province of Palencia (Spain), a large and predominantly rural area (out of 191 municipalities, only 1 has more than 20,000 inhabitants and 84% have fewer than 500 inhabitants[1]), the INTecum Project was designed and led by the Social Services Department (Junta de Castilla y León, regional authority) and implemented between 1st February 2019 and 30th December 2020. Its ultimate aim was to define a care model to provide the necessary social and healthcare services to 100 people at an advanced stage of illness who could and wished to remain at home, guaranteeing conditions of safety and quality of care.

Achieving this aim required the involvement, together with the nursing and medical staff of the hospitals and primary healthcare centres, of social workers and professionals with training in social intervention in such centres belonging to primary social care services and the entity providing the home-based services. These centres formed part of the public-private network set up to manage and implement the Project: the Regional Health Service (SACYL), the Regional Department of Social Services, the Provincial Authority of Palencia, the City Council of Palencia and the San Cebrián Foundation (a third sector social action body).

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[1] Official population figures resulting from the revision of the municipal census as of January 1, 2021, National Institute of Statistics: https://www.ine.es/jaxiT3/Datos.htm?t=2888

This networking made it possible to provide people and their families with three main types of services: actions to adapt the home to the needs of people at the end of life; technical aids to guarantee the mobility of sick people and the provision of care by their relatives or professional carers; and a personal assistance service to accompany the person and family carers. The effective provision of this care was delivered by means of a flexible and versatile support plan. The approach used was person-centred care and, consequently, maximum consideration and respect was given to the individual's preferences and expectations.

Mixed methodology and evaluative research.

While developing constructivist and comprehensive "fourth generation" evaluative research (Patton, 2015), a mixed research methodology was chosen (see Table 1) to identify the critical points of the project (especially those referring to its organisation and the care process) and to collect the assessments made by the different actors involved (in particular, the professionals involved and the people and families receiving the services and aid).

This combination is at the basis of processes oriented towards the generation of knowledge in social work that harmonise scientific rigour with the intention to be useful in decision-making for management and planning (Grinnell & Unrau, 2005). Likewise, it connects with recommendations in research on health and social intervention issues that agree on advocating quantitative and qualitative strategies simultaneously as a means of triangulation or of completing perspectives on the same object of study (Amezcua & Carricondo Guirao, 2000).

Research and analysis techniques.

Within the evaluative research framework of the INTecum Project, professional intervention in the social dimension of end of life care was defined as the object of study.

S*trategic case* selection was followed to form a non-probabilistic purposive sample and all health and social professionals linked to direct care within the framework of the Project and all beneficiaries (sick people and carers) of the actions implemented in the Project were identified as key informants (see Table 2).

A survey with two different questionnaires was addressed to all professionals —one applied during the implementation period of the Project and the other at the end— to obtain a total of 235 fully completed responses.

Likewise, 22 in-depth interviews were conducted with a small group of these professionals in the final weeks of the pilot implementation period; these interviews were held for 55 to 80 min, with an average interview time of 65 min. These professionals were selected according to the functions they performed in the Project until enough was achieved to represent the totality of the professional profiles involved in the intervention teams and their different tasks and responsibilities: organisation, management, and direct intervention. They were social and healthcare professionals; they had direct home care responsibilities or were intermediate coordinators of social and health services; they had participated in the Project at any time during its implementation; and they worked in rural and urban settings.

A total of 114 semi-structured interviews were carried out with the sick people and caregivers, most of them direct relatives (spouses or children), at two different times: before and after death. The three instruments were validated by means of a pre-test or pilot test to determine whether the questions were understandable, whether they caused fatigue or rejection, whether the duration was suitable, etc. and any appropriate corrections were made. Semi-structured interviews were held for 40 to 50 min, with an average interview time of 45 min.

The survey of professionals was sent by email in the days following the social intervention with the patient and/or caregiver. In order to ensure responsive interviews (Rubin & Rubin, 2005) in friendly environments that facilitate a climate of trust and security, the semi-structured interviews with patients and caregivers were conducted in the homes of the individuals until the covid-19 pandemic; thereafter, they were conducted by telephone following health authority recommendations.

Results

With the consent of all participants, the interviews were recorded and subsequently transcribed, providing material of very high quality that was sorted, coded and analysed using Atlas.ti software. After a first thematic analysis, an analysis was carried out in which the discursive dynamics were reconstructed, analysed and interpreted in the light of the different contributions. This process generated a set of 3 thematic categories and 9 subcategories, as shown in Table 3. The first thematic category addresses the assessment of the importance of the social dimension of end of life care in terms of its objectives and estimated relevance. The second and third categories analyse the role, competences and qualities of social workers in the provision of such care.

The social dimension in end of life home care: objectives, effects and assessment.

The professionals participating in the INTecum Project assessed the contribution of the social dimension of end of life care in achieving three objectives: providing support to people at the end of life so that they can remain at home with guarantees of quality and safety; improving their quality of life and positively influencing the course of their illness; and supporting the family unit in the process of adapting to the illness and bereavement. 75% of the professionals who responded to the survey scored the achievement of these objectives between 8 and 10 on a scale of 0 to 10, where 0 meant "not at all" and 10 meant "totally".

This highly satisfactory assessment was given by both health and social workers. Some social workers who had previously been involved in the provision of palliative care from a strictly healthcare perspective highlighted the interest and timeliness of the innovative experience.

> “I was already familiar with palliative care because I spent many years working in the social and healthcare unit and we saw we were not up to scratch in it. There were gaps that we—the doctor, the nurse, and the social worker—were unable to fill. The social part seemed fundamental to us; it was what we were asking for from the beginning” (Basic social services social worker).

The professionals of primary health and social care services (health centres and basic social services) who were aware of the initiative and participated, in one way or another, in the follow-up or care of the cases were very positive in their rating of the effects of the support provided by the Project on the people and their families: 86.4% of health professionals and 78.5% of social professionals considered the impact of social care on the quality of life of the persons and their informal carers as "relevant" or "very relevant", while only 0.8% of the former and 3.5% of the latter opted for the qualification of "not relevant at all".

Both types of professionals considered the impact on two very distinct levels: an ethical level, which has to do with guaranteeing their capacity to decide where the moment of death should occur, with recognition of their dignity as persons; and a level of maintaining their quality of life during the final stage in terms of guaranteeing safety, comfort and well-being.

> “The most important achievement is to give dignity to the person at such a vital and important moment of their life, and to their families. Giving them dignity in their own home and being treated well” (Social worker in primary social care).
>
> “It’s very important to enable you if you want to be in your house, in your home, in your environment, to be able to do so with quality. Families felt they were in a fragile situation in which they couldn’t provide the response that the patient sometimes demands, because they do not feel safe or supported” (Social worker in hospital centre).

The benefits perceived by professionals for the relatives of people at the end of life are identified in terms of emotional accompaniment, support in making arrangements, respite in care provision, safety and peace of mind when facing the different phases of the illness, etc.

> “That they can choose to be in hospital or in their own home, with facilities to keep calm, that they do not lose their environment, their roots and that the family is protected” (Social worker at a primary healthcare centre).

The people in the advanced stages of illness and their family members who were interviewed expressed a high level of overall satisfaction regarding the care received both before and after death, with scores of 9.3 and 9.6 respectively in each phase, using a scale from 0, indicating the lowest level of satisfaction to 10 the highest. Furthermore, all interviewees (100%) felt that their initial expectations when they joined the Project had been met. In their reflections, they highlight the special importance of professional care (personal assistants, case managers, health and social services staff) and the benefits perceived in the quality of life of both the sick people and their relatives:

> “I think it’s good that they are concerned about people like us, about people ending their days at home. We are all people who are terminal, incurable palliative patients, and we get worse every day. And it is a support to have a

> programme like this. It is a support that if you feel bad, you know there are professionals who can take good care of you at home" (Case KB).

Social work in end of life care: tasks, roles and training needs.

The social work professionals involved in the INTecum Project assumed different roles and responsibilities (see Table 4) depending on the institution they belonged to: health centres, basic social services or the service provider. Their contribution was relevant for the provision of the support and services envisaged in the Project: adaptations in the home, technical aids, community-based services, care and training of the carer and bereavement care.

The care process defined by the project involved the participation of social workers in its different phases. The list of their duties shows the variety and diversity of responsibilities and tasks assumed. Some professionals were in charge of managing entry onto the Project of possible candidates, providing information to those who, having joined the palliative care system, had been discharged from hospital or were already in their own homes. These same professionals provided the case managers with sufficient information regarding the conditions of the person (disability, dependency, performance of basic activities of daily living, etc.) and the socio-family situation (family composition and dynamics, carers, economic and housing conditions, etc.), thus contributing to the appropriate assessment of the social needs of the person and their relatives.

> "We were the gateway to the project; we detected potential candidates, evaluating whether they had the profile or not and doing all the paperwork. Our role there was to speak to the doctors, approach the families, coordinate and clarify the information about the resource. In many cases, the family needed time to think about it" (Social worker in hospital centre).

The social workers linked to the service provider, taking on the role of case managers, carried out the assessment of the home which, together with the aforementioned socio-family assessments, were the basis of the definition, agreed with the person and their carers, of the provisional support plan. From this moment on, the provision of support was simultaneous with the design of a care plan which would be applied until the moment of death.

> “What I’ve done is to assess whether they had that need. I’ve put them in contact and coordinated with the health centres and, when I’ve seen there was a more pressing problem, I’ve referred them to other teams. I’ve also had the job of providing information and guidance on economic benefits” (Social worker in primary social care).

Given that inter-institutional coordination is a key element to ensure comprehensive, integrated intervention in end of life care, this was, from the point of view of the social workers, a basic task in their duties. According to their contributions, coordination was easier and more effective between social workers than between social workers and health staff because they shared the same language and technical references. However, the affiliation of the professionals to units of the systems (health and social) that have different procedures, information technology (I.T.) tools, equipment and even zoning, made coordination in the Project complex, limited and, consequently, gave it ample room for improvement.

> “We form systems in which even the zoning is different, and at an I.T. level too, the profiles, the data protection issues… there are a lot of handicaps. We reached levels at which we were collaborating, working as a team in projects to facilitate, but I see it as very complicated” (Social worker in primary social care).

The high demands of the functions and tasks assumed by social workers, many of whom were not previously familiar with end of life care, explains the high degree of consensus that this should be a preferential training area for all professionals working in this field. Some statements made by social workers from primary social care services participating in the INTecum Project reveal the limitations perceived in a professional practice for which they had not received specific training. The nature of the needs to be addressed by these social workers was far from the usual ones in their institutional context and they did not have immediate professional references due to the innovative nature of the Project itself.

> "Here, I have a gap: I don't know if the figure of the social worker can carry out the role of accompanying, informing, providing economic benefits. Both the person and their carers often have a lot of doubt; they have no idea what steps to take" (Social worker in primary social care).

Although, according to their suggestions, training should cover knowledge about the problems and needs faced by people and families in this situation and about the most validated models of intervention, there is a predominant insistence on improving training in ethical issues and in the emotional accompaniment of both the person and their relatives. This training, according to some professionals, should also focus on revealing the space open to social work in end of life care from a community perspective, aimed at reinforcing social networks and mutual support practices.

> "We as social workers had been left to one side in the issue of assessing dependence and this gives us another role, a very good one. But basic social services could run some kind of information campaign, training, awareness for community-based social workers, spreading information about it and believing in it" (Social worker in primary social care).

Qualities and competences of the social workers from the perspective of the participants.

In social care dealing with end of life, social workers contribute, through their technical and methodological knowledge, their relational skills and their ethical attitudes, to ensuring that people have sufficient resources to face these circumstances within a framework of respect and empowerment. The information gathered within the framework of the INTecum Project has made it possible to evaluate how the people assisted and their relatives rate the most relevant elements in the performance of these professionals. Above and beyond issues related to technical skills and methodological or instrumental competence, the interviewees emphasise four types of professional qualities in their discourse which are given here in no particular order that would imply a criterion of priority.

Among the qualities recognised by people and their families are speed and availability in the process of helping. It could be said that not only is it important and decisive to configure institutional mechanisms that allow the provision of a rapid service (a condition attributable to the organisation of the Project), but that this would not be sufficient without the diligence and agility of the professionals who manage them. In this case, the professional becomes a reference point for the people who receive the support.

> “It’s clear to me, the attention, the speed of the support. That you speak to someone and in a few hours or the next day they are with you. That’s effectiveness. That’s what stays with you in the end: that they have helped you with everything and done it quickly. If my mother had any queries, they were always there to solve them. Everything has to be highly valued. And in situations with palliative patients, it’s valued even more” (Case WAH).

Another of the qualities appreciated in the actions of social workers has been kindness, the gentleness in their approach, an element that contributes to humanising the end of life. The extreme importance of personal communication style as the basis of the professional relationship is well known. Undoubtedly, this becomes key in end of life care and emerges as a central element in the comments made by the people cared for. Their own words evidence the perception of support in terms of tranquillity, security and relief that this professional approach entails.

> "There is an important technical part, but what I would highlight above all is the work to humanize the services. A lot of care is taken over this aspect. And the compensation for this is in the improvement in the patient's quality of life and in ours, as caregivers. If the professional care was not correct, like I say, humanizing, then the adjustable bed and mattress would be of little use" (Case WEL).

On a level that connects with the ethical dimension of care, the people cared for at times when they are particularly fragile also value respect for privacy, confidentiality, and self-determination, which are basic principles of social work. On the one hand, for people who have not always had their right to privacy recognised when writing reports, filling in forms or facing various administrative requirements, professional practice that puts this principle first is considered to be of particular importance. On the other hand, self-determination, understood in the Project as the capacity of the person to make decisions about their care plan and, particularly, about their preference for the place in which they die, highlights the important role of the professionals of social intervention on three levels: offering the necessary information to the person; if necessary, mediating between the person and the relatives and/or between both and the personnel of the health services; and, finally, organising the necessary support for the fulfilment of the wishes expressed.

> "We were constantly saying, 'how lucky we've been,' because their wish was to be at home. They had all the support to make that possible" (Case BH).

Finally, in fourth place, the interviewees emphasised the attitude of listening and constant attention to people's needs and demands and the practice of accompaniment as particularly relevant qualities among social workers. The first is linked, in the statements collected, to the feeling of being respected, understood and, consequently, being attended to in terms of the needs required at any given moment. The second is recognised as a way of understanding the relationship with the professional in which guidance, advice and trust take precedence, and where the help is constantly seen to be reviewed and adapted. In advanced illnesses, in which conditions very often change suddenly, the attitude of attentive listening becomes essential in order to provide accompaniment that is perceived as effective and satisfactory.

> “The truth is that the help you have, that you feel listened to, you also feel valued. And, sometimes, you get things off your chest because you don’t want to worry your family and then… For example [the practitioner] had come for half an hour and has been with me for over an hour, listening to me. I noticed that, and it means a lot. Afterwards, perhaps, she rushes off to somewhere else, but I have felt she’s been listening to me and that means a lot” (Case EQ).

Discussion

The research work undertaken has allowed evidence to be gathered on the importance of end of life social care at home, and on the view that the professionals involved in that care and the people who receive it have of the role, functions and qualities of social workers.

In line with the conclusions of recent systematic reviews of international scientific literature on end of life care (Ahluwalia et al., 2018; Spelten et al., 2021), the research has shown the interest and relevance of home care. Shifting end of life care from the hospital setting to the home has enabled the participants in the INTecum Project to express and make effective their preference about the place and environment for their last days. That shift has also made it possible to assess and respond to their social needs and has facilitated the implementation of person-centred care, avoiding disconnection from their natural support and community networks.

The results of our research have also confirmed, as recent work has shown (Sagha Zadeh et al., 2018), that this care is better valued and more effective when it is provided as a multidisciplinary approach and with consistency among care providers, including administration, clinical management, front-line caregivers, and support staff.

Within the framework of multidisciplinary teams of this innovative project, social work professionals in primary healthcare centres, hospitals, basic social services centres and, particularly, social workers with the profile of case managers have taken on tasks of information, guidance, accompaniment, mediation and support for sick people and Sptheir families. These tasks reveal that social work is a profession well placed to incorporate a perspective centred on the patient, their family and their community setting (Jones et al., 2014; Delgado Reguera, 2019). This conclusion concurs with the evidence gathered in studies according to which, in interdisciplinary teams made up of medical, nursing and social work professionals, the social workers have more conversations with patients about the care they will need in the future, are the professionals who most frequently discuss with people the pros and cons of hospital versus home care, and are positioned as the practitioners who interact most frequently with family members and their social networks (Wang et al., 2018).

A fundamental finding of the research process has been the relevant role played by social workers in assessing the psychosocial situation with people and families in crisis, in such exceptionally sensitive situations (Hernández Moscoso & Toro-Pérez, 2020). As F. Fantova (2017) suggests, the professional care that a person should receive belongs to the sphere of their moral autonomy and decision-making capacity or that of whoever legitimately represents them, but this decision can and must, under certain premises and in certain contexts, receive a professional assessment that allows the best adjustments to be established between professional care, self-care and primary care. Within the framework of the innovative project, the social work professionals in the health and social services centres have provided the case managers with information on the socio-familial situation of the sick people. These professionals have reached consensus with those people and their relatives, first through provisional support plans and then through care plan, about professional care to complement that provided by informal carers. If the case study documented by García Aguña (2021) has shown how social workers can approach this professional assessment in a palliative care unit of a public hospital using the crisis intervention model as a reference, the research undertaken in the INTecum Project has evidenced how social workers can contribute to this assessment in the home environment using a person-centred, comprehensive care model (Librada et al., 2015).

Qualitative studies that have assessed patient and family satisfaction regarding the care received (Morrs Dy et al., 2008) have highlighted the importance of considering their social situation as a basic element of individualisation that guarantees people are treated in a holistic way (not as a disease) and cared for as unique individuals (respecting their values and ways of life), and that their family is included. From this point of view, social workers, applying ethics and values at times when respect for self-determination is fundamental (Wesley, 1996), have favoured the recognition of people's dignity, have supported them in making their decisions effective in their care plan, and have contributed to the humanisation of the end of life.

The list of tasks carried out by social workers within the framework of the INTecum Project that were documented by the research team has made it possible to identify their different roles in the direct intervention with individuals and their families. These coincide with those described by Bern-Klug et al. (2001): clarifier, counsellor, mediator, resource facilitator and manager, defender of personal and family interests, and team member. The contributions of some social workers stress that taking on these responsibilities has meant a reorientation of social work towards the so-called "primary activity - face to face", typical of the world of real life and rooted in the origins of the discipline (understanding, participation, communication), as opposed to the often over-dimensioned "indirect social work activities", typical of systemic logics (management, administration, bureaucracy) (Ballestero Izquierdo et al., 2013).

On the other hand, the testimonies collected from the participants have revealed the important role of social work professionals when they adopt an attitude of active listening and accompany by offering availability and kindness and respect for people's privacy. These ideas are in line with the contributions of Idareta-Goldaracena (2021) which state that being a good social work professional implies displaying qualities or ethical virtues such as respect, care, compassion, kindness, trust, competence (technical, ethical and emotional) and humility. This professional approach distances itself from a 'top-down' model of end of life care that focuses on formal services (Hudson & Payne, 2009), that sees people as packages of needs to be met by professionals and that removes the recognition of people as fully social beings who live and die, care and are cared for, within a natural relational framework (Brown & Walter, 2014).

The research results allow us to defend social work intervention models in end of life care that advocate the optimal alignment of professional know-how with the empowerment of people, their caregivers and the natural networks of which they are part

(Adshead & Dechamps, 2016). This assumption underpins community empowerment agendas (Kellehear, 2013; Rodríguez Prada et al., 2017) and projects to promote volunteering (Sendra & Vara, 2010), which were not sufficiently explored in all their dimensions in the INTecum Project.

Finally, the evidence gathered in the study has confirmed that most social workers do not feel adequately trained to practise in the field of people with advanced illness (Wang et al., 2018). Professional social workers call to be trained in knowledge as varied as the legal principles involved in end of life care and the psychological, physical and social impacts on caregivers. They also need training in skills to help people and their caregivers in the assessment of the situation they are facing, to facilitate the choice of the support they will need, both formal and informal, or, for example, to work on community education and mobilise latent social resources in the community. There has been a clear demand for training in values and attitudes of respect for the person's weaknesses and wishes, sensitivity, compassion, respect for dignity, confidentiality and, especially, in ethical knowledge, skills and virtues that will enable them to face the frequent problems and dilemmas that arise in professional practice linked to care of this kind (Dewar et al., 2023).

Limitations of the study

This study presents some methodological and content limitations that should be taken into account in order to generalize its results.

On the one hand, the size and profiles of the sample used have been conditioned by the limited number of cases selected and attended by the project and by their limited cultural, age and habitat diversity. On the other hand, the absence of validated scales for the evaluation of the care provided by social workers working in end of life care has forced the construction of ad hoc instruments, which makes comparison with similar experiences at the national and international level difficult.

Finally, the paper barely explores the important roles that social workers have in the community dimension of end of life care: fostering volunteerism, supporting secondary social networks, building compassionate communities, etc. This area of work is undoubtedly very relevant in professional intervention for the provision of this kind of care.

Conclusions

This work has made it possible to analyse four key trends in end of life care: the definition of comprehensive, integrated, shared and continuous care processes (in which social needs, together with medical and nursing needs, are given special recognition); the establishment of socio-health structures for the provision of care in which multiple agents are combined (from public health services, social services, educational services, etc. to third sector social action organisations, volunteers or different community groups and networks); the formation of interdisciplinary teams with the participation of professionals in medicine, nursing, social work, occupational therapy, psychology, etc.; and the shift of end of life care from the hospital to the home (responding to the preferences of the majority and enabling care centred on the person, connected with their natural networks and integrated with all other resources available in their locality).

On the basis of an innovative initiative described in this article, it has been found that both the professionals involved in the social and healthcare teams and the people receiving their support consider that social home care at the end of life improves the quality of life of sick people and their families, has a positive influence on the course of the disease, helps them in the process of adapting to the demands of the disease, and allows them to remain at home with guarantees of quality and safety.

Likewise, there has been recognition of the roles of the social workers present in the teams providing home care at the end of life and those who form part of the network of community-based social and health services who are called upon to participate in the provision of such care. As mentioned previously, those roles include clarification, advice, mediation, resource management, team membership, and facilitate a person-centred perspective that does not neglect the relational and community dimension. Their contribution has been valued in terms of the management of services and support (speed, availability, kindness, sensitivity), the establishment of teamwork (coordination, facilitation) and, above all, the recognition of the basic principles of the care process (individualisation, self-determination, humanisation). Professional practice of this nature fosters functions which, both from research (discipline) and from intervention (profession), have been recognised as identifying features of social work and which, paradoxically, have been losing ground in certain institutional contexts due to the preponderance of bureaucratic and management tasks.

In addition to these aspects, the research work has made it possible to identify some lines of study and reflection still to be developed on the performance of social workers in end of life care. Among others, three can be highlighted: the models and strategies of community intervention to be explored for the reinforcement of primary networks; the training needs of social workers to face the technical, methodological and ethical challenges of their role; and the professional competences that social work can assume in the development of a network in which social services, health services and social community-based entities participate.

Research Ethics

This study follows the internationally accepted ethics in research with human participants of the American Psychological Association (Sales & Folkman, 2000).

Pursuant to prevailing Spanish legislation (Organic Law 3/2018), the participants received information about the study objectives, its voluntary nature and gave their consent for the data obtained to be used for the research. Also, the necessary measures were taken to ensure the confidential treatment of personal information (anonymity of collected material through secure encryption, hosting on protected servers, etc.). To guarantee compliance with current legislation on research ethics, before the evaluation process began, a statement on ethical implications was made before the Office of the Vice President for Research, Innovation and Transfer of the University of Valladolid.

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Conflict of Interest

The authors confirm that they have no conflict of interest in respect of the material submitted in this article.

Authors’ Contributions

All authors contributed to developing and testing the interview instrument, conducted the interviews and coded the texts, and all authors reviewed coding for major themes. Juan Mª Prieto Lobato conducted the in-depth analysis of coded materials and wrote the manuscript with input and final review by Pablo de la Rosa Gimeno, Carmen Rodríguez Sumaza, Alfonso Marquina Márquez y Jezabel Lucas García. Juan Mª Prieto Lobato y Pablo de la Rosa Gimeno led the overall study.

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Table 1. Technical sheet of the study.

Object:	Social work in the social dimension of end-of-life care
Methodology:	Mixed, Quantitative and Qualitative Evaluative Research
Techniques:	Questionnaires filled out by the respondents In-depth interviews Semi-structured interviews
Key informants:	Social workers Healthcare professionals (doctors and nurses) Patients, family members, and caregivers
Data collection:	From 1st February 2019 to 30th November 2020
Data processing:	Excel Atlas.ti

Source: The authors.

Table 2. Key informants, research techniques and evidence collected.

	Research techniques		
Key informants	**Questionnaires**	**In-depth interviews**	**Semi-structured interviews**
Primary social care professionals	71	4	-
Primary healthcare social workers	67	2	-
Hospital centre social workers	3	3	-
Social case managers of the service providing entity	-	3	-
Management and coordination officers in social services and health services.	-	3	-
Patients and caregivers (before death)	-	-	40
Carers (after death)	-	-	74
Primary healthcare doctors	39	1	-
Primary healthcare nurses	58	3	-
Total	**235**	**22**	**114**

Source: The authors.

Table 3. Thematic categories and subcategories.

Social dimension in end-of-life home care	Objectives Relevance
Social work in end-of-life care	Role Interprofessional coordination Training needs
Qualities and competences of social workers	Speed and availability in the helping process Kindness and sensibility when dealing with people Respect for privacy and self-determination Attitude of listening and accompaniment

Source: The authors.

Table 4. Responsibilities assigned to social work professionals in the INTecum Project.

Hospital and primary healthcare centres	Primary social care centres	Entity providing the home-based services
· Detection and inclusion of people to the Project. · Information and document gathering for joining the Project. · Social assessment of the case. · Follow up of the healthcare received by each person.	· Social information about the people included in the Project. · Coordination with the health case coordinator. · Approval of the provisional support plan. · Approval of the proposed intensities · Coordination of social and healthcare. · Monitoring and supervision of the care plan. · Management of basic benefits · Coordination and management of support in the neighbourhood.	· Assessment of the risks at home. · Drafting of the provisional support plan, the life story and the care plan. · Provision of community-based services, technical aids, and adaptation to the home. · Coordination with direct care professionals. · Support and preparation for the family and immediate environment. · Follow up of the direct care. · Bereavement care

Source: The authors with information from the Junta de Castilla y León, regional authority 2019.