Palliative Care in Older People with Multimorbidities

Although numerous studies have been conducted on the needs of cancer patients at the end of their life, there is a lack of studies focused on older patients with non-oncological complex chronic multipathologies. Examining these needs would help to gain a greater understanding of the profile of this specific population within the palliative care (PC) pathway and how the health and care systems can address them. Substantial changes are needed in health and care systems at the institutional level to provide more specialized PC environments and systematized PC processes for multimorbid older patients. It is vital to understand and address the needs of multimorbid older patients and their caregivers given that the number of these patients is growing, which may challenge current healthcare systems.

1. Introduction

The palliative care (PC) concept has undergone changes and evolution in related conceptual and strategic approaches, including their use in clinical practice, in recent years. Conceptually, in 1990, the World Health Organization (WHO) adopted the definition proposed by the European Association for Palliative Care (EAPC) as the total active care of patients whose disease does not respond to curative treatment. The control of pain and other symptoms, as well as psychological, social, and spiritual problems, is paramount. The WHO subsequently expanded this definition, currently taking the form of: “An approach that improves the quality of life of patients and families facing life-threatening diseases, preventing and mitigating suffering through early identification, pain assessment and treatment, and other physical, psychosocial and spiritual problems” [1].

According to this definition, the delivery of PC should be guided by the improvement in patients’ and their families’ quality of life. Additionally, PC aims at facing needs associated with life-threatening conditions and trying to prevent and relieve suffering through several actions in the continuum of care: early and timely identification, adequate assessment and treatment of multi-domain symptomatologies. PC is applicable at the onset of the disease, alongside other curative therapies. This integration of PC has been developed mostly around the oncology area as most of the PC protocols, programmes and units are more focused and addressed to patients with cancer. However, the rate of older adults (60 and over) in need of PC with non-oncological diseases, such as Chronic Obstructive Pulmonary Disease (COPD), diabetes, cardiovascular disease and renal diseases [2] among others, is higher than those with cancer [3], and additionally, when they are admitted to PC units they tend to be closer to death than those patients with cancer [4]. It has been reported that patients with advanced cancer experience improved quality of life and symptom intensity with early PC interventions compared to those who only received cancer care alone [5][6].
Chronic diseases represent around 70% of deaths worldwide [1]. The increased incidence, prevalence, and mortality of chronic diseases and multimorbidities, defined as the presence of two or more long-term health conditions [8], place a significant challenge on PC resources and a burden on health policies and practices [9]. As an increase in the rate of older people with complex chronic diseases is expected over the next 25 years, early identification of PC needs among older patients with comorbidities is becoming an important concern for health systems in order to provide comprehensive care that meets the needs of both patients and family caregivers, considered by the WHO as an indivisible unit in the provision of PC. Ensuring that family caregivers’ needs are appropriately assessed is one of the top quality markers for end-of-life care [11], due to them being critical to the patients quality of life.

2. Patients’ Needs

2.1. Emotional/Mental Needs

Most of the needs reported were related to emotional and/or mental dimensions, such as social isolation, depression, anxiety, or feeling like a burden on families [12] [13] [14] [15] [16] [17] [18] [19].

2.2. Physical Needs

Patients reported that needs at the physical level caused less concern, as they were often considered covered by health providers through therapies or treatments. However, the most commonly reported physical needs were pain, fatigue, restlessness and agitation, and limitations in activities of daily living [12] [13] [14].

2.3. Information Needs

A lack of enough information was also reported in several studies, highlighting the need for more information about PC and related resources [20] [21] [22] [23] [24] [25], as well as the need for information about the progression and severity of their disease [26] [27] [28]. In line with information gaps, communication with health providers was also detected as an area for improvement, as patients consider it necessary to improve relationships and effective communication, for instance, to feel more supported in finding PC providers [28] [29] [30] [31] [32] [33].

2.4. Spiritual Needs

Some studies revealed the need for spiritual care [32] [16] [33] [34] [18] [35] [36], although these were approached from different perspectives, with some studies mentioning the need for spiritual attention without specifying more about it [32] [34] [18] and others referring to more specific aspects of this concept. In this sense, patients can feel distress if their religious wishes and values are not attended to, and being able to discuss spiritual beliefs was indicated as highly important to many patients [16]. Patients felt that clinicians lacked knowledge about cultural practices, such as rituals and religious aspects considered highly sensitive and necessary in end-of-life care [33] [35] [36]. In some cases, spiritual care was considered to be the possibility of talking to religious leaders, or as providing a safe space, communicating with sensitivity about spirituality, listening, and counselling [35].

2.5. Other Needs

Other needs, such as specific cultural needs, were also mentioned, as well as clinicians’ lack of cultural awareness and the potential breadth of cultural practices, rituals, and other cultural patient’s needs [33].

The need for an adequate environment, with privacy and dignity, as well as the preference for receiving care in the same place and by the same clinicians in order to become comfortable with
the environment and to minimize distress, especially in cases of patients with dementia, were also reported [32][34][36][24][37]. Moreover, the appointment of a key worker acting as a point of contact for the patient and family was considered relevant for continuity of care, avoiding confusion, and maintaining continuous contact [38].

| 3. Caregivers’ Needs |

3.1. Emotional/Mental Needs

Similarly, to patients, some of the needs pointed out in the studies by caregivers were those related to emotional and/or mental aspects, such as sleep problems, stress, confinement, physical strain, or anxiety [32][30][28]. They also desired emotional support and educational courses regarding how to handle emergency situations, e.g., falls and psychosis or medications, and more information about disease progression and what to expect in the future [41][42][43][44].

3.2. Physical Needs

Caregivers indicated the need for more respite services or personal outings to deal with fatigue and strain [41][40].

3.3. Financial Needs

Other needs related to financial concerns were also mentioned in some of the studies. Some caregivers had to leave their paid employment to provide full-time care and use their savings or accumulate debt derived from paying for care for their family member, the costs associated with long-distance travel, medications, home care, accommodation, and the rental of equipment necessary for the care of the patient's needs [42][15][39][30][45][31].

3.4. Social Needs

Social needs were also detected in those studies related to the impact of caring on caregivers social life. These studies stressed the loss of and decrease in caregivers social contacts or the experience of isolation from friends, neighbours, and the community as a result of providing full-time care [12][42][39][45]. Social assistance needs to obtain resources or benefits, such as direct financial support or social services to alleviate the burden of care, were also mentioned [42][15][45].

3.5. Other Needs

Some studies reported that family caregivers felt that the amount and type of information received about their patients’ health were inadequate and insufficient [42][46][22][44][19][28]. Some studies pointed out that caregivers consider care providers to be mainly focused on the medical aspects of care and that they tend to exclude the psychological, emotional, practical, and spiritual domains [16][45][33]. In this line, spiritual care was reportedly lacking, due to staff members lack of time and their lack of prioritization of this aspect of care; consequently, caregivers reported the need for spiritual care for patients and themselves and the need to have time to talk to clinicians about this [32][41][49][43][47]. Furthermore, more time and human connection with professionals, effective communication, and shared decision making were indicated as important [48][22][43][19].

Some studies reported that caregivers feel that they do not have enough information about PC services and how these can provide more comfortable care [38][49][43][50][51][19]. Regarding discussing end-of-life care preferences together with healthcare staff, some studies reported that family members would like to be more involved in medical decisions [31][42][28]. Caregivers often felt that medical staff, such as nurses or doctors, do not have enough time to listen to and discuss their relative’s condition with them, becoming a source of distress to families who feel under
pressure to make the right choices [32]. One study emphasized concerns about combining work with caring for their family member, highlighting the need for remote working and flexibility in working hours [51].

Lastly, other studies highlighted bereavement support as an important need for caregivers. Carers described the continued need for support in the period soon after death [32][43][51], and remarked that palliative care provision should be extended to support family carers [38][41][43][45].

4. Professionals’ Needs

4.1. Needs in PC Provision

On the one hand, professionals identified barriers to providing effective PC to this group of patients. In some studies, professionals pointed out that patients with non-malignant disease were less likely to be referred to PC services due to the historical link between cancer and palliative care [52][53][54]. In other studies, professionals highlighted that patients suffering from non-cancer diseases often receive inadequate care, with poor communication between the different services that care for them, and also shared that there are fewer specific services for these patients compared to for cancer patients [55][24]. A lack of staff to provide sufficient care to patients, resulting in little time to properly address PC needs, was highlighted by some studies [34][58][57][59].

(a) Referral to PC

Often, multimorbid patients are referred to PC units in the terminal stages of their disease; thus, professionals consider it necessary to initiate these referrals earlier to promote continuous care [59][60], especially with older patients [55], patients with Chronic Heart Failure (CHF) and COPD [61][62], and patients with conditions other than cancer [53]. Moreover, professionals do not always know who has the responsibility to care for CCC patients in need of PC, and often the roles are not defined, which causes fear of starting conversations about palliative care with the family or the patient [63][64][54][65].

In this sense, some of the studies showed a lack of homogeneous referral criteria, protocols, or pathways to initiate PC services [66][67][68][62]. Additionally, professionals pointed out that there are barriers to referring PC patients and interspecialty dialogue, with a lack of communication between different specialists resulting in professionals only partially knowing the pathologies that can occur in patients and preventing or delaying referral to a PC itinerary [69].

Moreover, in some studies, professionals expressed that there is complexity in prescription and treatment approaches due to the impact of the complex comorbidity profiles of multimorbid patients, such as the effects of drugs in older populations (unforeseeable interactions or side effects) [55][65].

(b) Comprehensive and continuous care in PC

Professionals considered that a holistic approach to patient care is crucial, starting when curative treatment is no longer realistic, rather than focusing only on physical symptoms [70][21][62][56][71]. The necessity of going beyond the management of pain was underlined, as patients and their relatives’ non-physical needs, such as spiritual and emotional needs, were considered to need further support [70][62].

Some studies also pointed out that professionals need more time and continuity in the attention given to their patients, having time to talk calmly with patients and their families about PC decisions and needs [66][72][58][73][74]. The pressure of having less time was indicated as causing a feeling of not being able to talk with or attend to patients in a comprehensive way [72][73], and lack
of continuity was pointed out as a major threat to PC attention, especially for people with severe dementia [75][80][60]. Two studies remarked on the need to take into consideration the biography of each patient, and reported that practitioners considered that they only overviewed fragments of care among older patients, which makes the provision of individualized care adapted to patients’ needs difficult [67][55].

Some studies also remarked that adequate time is not available for professionals to be able to start conversations with relatives and patients about care planning and advanced directives [54][62]. Two studies stressed that professionals lack knowledge and belief in the role of advanced plans, since many changes can take place in the medium and long term [26][60]. It was also pointed out that there is a need for an objective measure to identify caregivers at risk of poor bereavement [77][79] and dedicated staff to take responsibility for bereavement care [77][40]. Furthermore, a need for formal assessments of bereavement instead of using only observations, intuitions, or informal conversations was highlighted [77].

A proactive multidisciplinary approach (combining clinical psychologists, social workers, and psychiatrists) and interprofessional collaboration [52][54][18][59] were described as important in PC to increase CCC patients’ and their caregivers’ wellbeing [67][68][79][58][80][65]. Moreover, new specialized structures for PC geriatric patients were considered necessary to be able to address the specific needs of patients with multiple needs [55].

4.2. Training Needs

On the contrary, several training needs were detected. Special reference was made to specialized training in PC, highlighting that professionals may feel they have a lack of skills for good communication with patients [27], the need for additional palliative and end-of-life care education [20][81][57][80], more awareness and understanding of PC, as well as further training on how to identify patients’ needs and understanding of end-of-life care [54][58]. Additionally, several studies highlighted the lack of knowledge of the palliative needs of different groups of patients, such as those with COPD [73], severe dementia [12][50], disabilities [66], or complex comorbidity profiles [69]. Some studies stated the need to move toward early PC conception, as many professionals recognized that their perception of PC was associated with care during the last days of life [82][49][83]. Furthermore, one study highlighted the need for advanced training in early PC [61].

Some studies also pointed out professionals needing emotional support to prevent burnout and delineating emotional and professional boundaries [84]. One study highlighted the need for self-care in coping with death and dealing with professional grief [66], as some professionals felt that their grief is inappropriate or that they do not have time to express it [78].

In this line also, healthcare professionals remarked on the importance of spiritual care and having the skills to address it [70][79]. However, it was pointed out that professionals felt fear of being unable to resolve spiritual problems and experienced difficulties in communication about spiritual needs due to a lack of knowledge around such issues [85][36]. Additionally, they highlighted that assessment tools for spiritual needs are not taught during the received training [85][36]. Moreover, practitioners and nurses indicated a desire for support to address patients’ spiritual needs from other professionals, such as social workers, clinical/counselling psychologists, chaplains/spiritual care professionals, other alternative therapy professionals, and psychiatric professionals [58].

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