

# In Advance

## **D3.2 – Report on individual and contextual factors**

### **WP3 – Intervention modelling through equitable multilevel needs assessment**

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Quality Control	
<b>Author(s)</b>	
Yu (Maggie) Fu	UNIVLEEDS
Michael Bennett	UNIVLEEDS
Laura Llop	UVEG
Ascensión Doñate	UVEG
<b>Contributor(s)</b>	
<b>Editor(s)</b>	
Yu (Maggie) Fu	UNIVLEEDS
Laura Llop	UVEG
<b>Reviewed by</b>	
Sofia Reppou	AUTH
Vicente Traver	UPV-SABIEN
<b>Approved by</b>	
Project Coordinator	UVEG

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## List of Acronyms

<b>CINAHL</b>	Cumulative Index to Nursing and Allied Health Literature
<b>PC</b>	Palliative care
<b>WHO</b>	World Health Organization



## 1 Executive summary

The increased incidence, prevalence and mortality of chronic diseases and multimorbidity in older people challenge palliative care resources. Although the need to address individual physical, psychological, social and spiritual needs through holistic and person-centred care is internationally recognised, there remain unmet needs for palliative care and provision of palliative care varies in different settings. This scoping review was undertaken, as part of the intervention development of the InAdvance project, aiming to produce the initial summary on individual and contextual factors that impact on palliative care needs in patients with multimorbidities. A detailed analysis will be considered at a later stage leading to a published academic paper. A search strategy was performed in seven databases to retrieve relevant studies using any research methods. Eligible studies were those reporting needs, preferences and concerns of palliative care from patients, caregivers and health professionals. Data and findings of the included studies were extracted and narratively synthesised. A total of 5,968 records were identified and a subsample of 320 records were selected for abstract review, producing 41 studies in full text for inclusion. Needs identified were grouped based on stakeholders involved: patients, caregivers, health professionals and health system related factors. These were further summarised to themes, including physical needs, psychological and emotional needs, social needs, financial needs, accessibility to services and needs for education, training and support identified for all parties.

Although multiple sources of data were used enabling the InAdvance team to build on our existing understanding of stakeholders' needs in multimorbidities, needs or factors could not be sorted by specific health conditions. Therefore, careful interpretation is needed from partners involved with a specific focus of health condition.

Factors identified from this review are useful for the InAdvance project in understanding individual needs for PC provision in older patients with multimorbidities. Such needs and factors are also useful for developing the interview topic guide at a later stage for WP3 – qualitative study to explore individual needs for the integration of PC in the management of chronic illnesses. These may also be important to partners on this project who aim to develop interventions for supporting older people with multimorbidities. This review also calls for the development of a needs assessment tool (which the InAdvance project will be developed) to identify PC needs of patients and caregivers in a systematic manner, to enable the development of individualised integrated PC model for patients with complex needs.



## 2 Introduction

Older people living with multimorbidities often experience a range of debilitating physical symptoms combined with high levels of psychosocial distress. The increased incidence, prevalence and mortality of chronic diseases and multimorbidity challenges palliative care (PC) resources worldwide. According to the World Health Organization (WHO)(1), PC is aimed to improve the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of symptoms such as pain and other problems (physical, psychosocial and spiritual).

Although the need to address individual physical, psychological, social and spiritual needs through holistic and person-centred care is internationally recognised(2), there remain unmet needs in patients with multimorbidities and provision of PC for them is variable. Therefore, understanding individual factors including patients and caregivers' needs for support, and contextual factors including health care systems in providing PC for the management of multimorbidities in older people is key. Hence, a scoping review and a narrative synthesis of the current literature was carried out to identify individual and contextual factors impacting on PC provision for patients with multimorbidities.



### 3 Aim

This scoping review was undertaken, as part of the intervention development of the InAdvance project, aiming to produce the initial summary on individual and contextual factors that impact on PC needs in patients with multimorbidities. The scoping review was to respond to the following research questions:

1. What are the needs and factors influencing PC services for older patients with multimorbidities?
2. What are the needs and factors influencing PC services for caregivers of older patients?
3. What are the needs and factors influencing PC provision by health professionals for older patients and their caregivers?
4. What are the factors related to health system for PC provision?



## 4 Methods

### 4.1 Search strategy

Thorough searches were carried out in Medline, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Cochrane Library, PsycINFO and Scopus from the year 2009 to date. A range of keywords and subject headings indicating PC, older people needs, patients, families, non-formal caregivers, and health care professionals were used aiming to maximise the retrieval of relevant studies. The final search strategies used in Scopus is shown below as an example.

```
(((((palliative care [Title/Abstract]) AND patients [Title/Abstract]) AND needs [Title/Abstract]) OR preferences [Title/Abstract]) AND older [Title/Abstract] OR elderly [Title/Abstract])
```

```
((palliative care [Title/Abstract]) OR palliative care unit AND health professionals[Title/Abstract] AND perceptions [Title/Abstract]) OR needs [Title/Abstract]) NOT patients [Title/Abstract])
```

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((palliative care [Title/Abstract]) AND families [Title/Abstract] OR caregiver [Title/Abstract]) AND needs [Title/Abstract]) OR perceptions [Title/Abstract]) AND elderly [Title/Abstract]) OR aged [Title/Abstract])
```

### 4.2 Eligibility criteria

Any peer-reviewed studies published in the last 10 years using any research method research and reporting in the following subjects were included:

- Patients (over 65 years old or over) expressing needs/concerns for PC in the management of multimorbidities;
- Families or carers of patients expressing needs/concerns for PC services;
- Health professionals expressing needs/concerns for PC provision

Studies were excluded if they were:

- Studies reporting patients living with cancer or undergoing cancer treatments;
- Studies reporting views of the general public;
- Letter of opinion to peer-reviewed journals;
- Editorials or commentaries;
- Non-English language studies;
- Published before 2009;
- If the researchers have no access to the full text.

### 4.3 Study selection

Records identified from the electronic searches were imported into Endnote (Reuters 2011) to avoid duplication of the screening process. At the stage of screening, abstracts were retrieved if the title included reference provision of PC in the management of multimorbidities. If it was not clear from the title or the abstract, the full text was retrieved. Studies were excluded if they were clearly not full research reports, for example, conference abstracts, editorials or commentaries or news reports.

### 4.4 Data extraction

A form was designed to extract data including service context (country; outpatient, inpatient; generalist or specialist), participants (patients, carers or professionals), diseases and age groups of patients, main thematic findings related to PC provision and enablers and barriers.

### 4.5 Data synthesis

A narrative synthesis was undertaken that focused on identifying individual and contextual factors and enablers and barriers to the PC provision in older people with multimorbidities. Study findings and factors were examined and regrouped based on the related stakeholders.



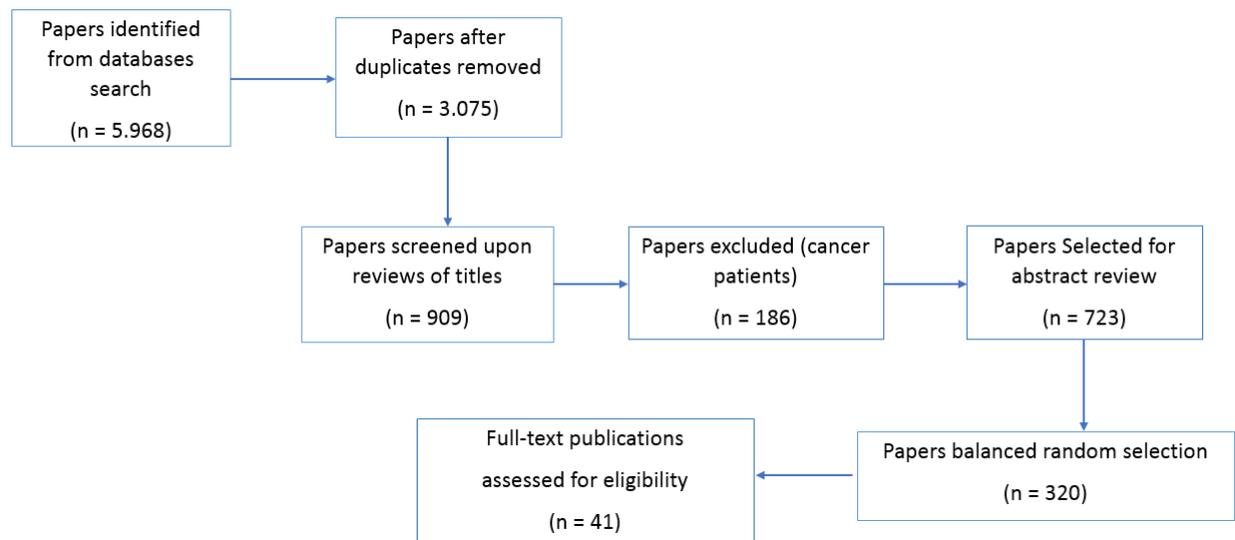
## 5 Results

### 5.1 Selection of studies

A total of 5,968 citations were retrieved by the initial search and 3,075 were included after duplicates were removed. Following the screening of titles, 723 records remained for abstract review. As part of the aim of this review was to produce an initial summary on individual and contextual factors, a total of 320 records were randomly selected to balance the coverage of studies reporting patients, caregivers, health professionals and system related needs and factors, for abstract review in order to inform the project in a timely manner. As a result of this, 41 records were retrieved in full text (figure 1). A detailed analysis will be carried out as a later stage leading to a published academic paper.



**Figure 1 Study selection flowchart**



## 5.2 Individual and contextual factors identified

Factors identified from this review were firstly grouped based on stakeholders involved: patients, caregivers, health professionals and health system. These were further summarised to themes mapping out the WHO definition for PC, including physical needs, psychological and emotional needs, social needs, accessibility to services and needs for education, training and support. Summarised findings are presented in Tables 2-5 on patient, caregivers, health professionals and system related needs and factors, respectively. Items presented in Tables 2-5 in no particular order.

**Table 2 Summarised patients' related needs of PC provision for older people**

Domains	Patient related needs and factors
Emotional/mental needs	<ul style="list-style-type: none"> <li>- Guilt, feeling like a burden for others.</li> <li>- Helplessness, loss of control.</li> <li>- Anxiety.</li> <li>- Stress.</li> <li>- Worry about the future/ family.</li> <li>- Questioning life's purpose or priorities.</li> <li>- Preferences regarding spiritual care.</li> <li>- Not being a burden to family</li> </ul>
Physical needs	<ul style="list-style-type: none"> <li>- Pain.</li> <li>- Fatigue.</li> <li>- Breathlessness.</li> <li>- Manage of symptoms</li> </ul>
Caregiving needs	<ul style="list-style-type: none"> <li>- Activities of daily living.</li> <li>- Homemaking tasks.</li> <li>- Nursing and personal care.</li> </ul>
Other needs related	<ul style="list-style-type: none"> <li>- Need for spiritual care.</li> <li>- Improve quality of life for the time left.</li> <li>- Home as the most preferred place of death.</li> <li>- Need of information about progression and severity of their disease.</li> <li>- More information about PC.</li> <li>- Help to find PC providers.</li> <li>- Improve communication</li> <li>- More information about provision of resources.</li> <li>- Nurse-led domiciliary visit.</li> <li>- Continuity of care.</li> </ul>

	<ul style="list-style-type: none"> <li>- Preferred to receive appropriate palliative care that gives comfort rather than to prolong life if being diagnosed to be terminally ill.</li> </ul>
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**Table 3 Summarised caregiver related needs of PC provision for older people**

Domains	Caregiver related needs and factors
Emotional/mental needs	<ul style="list-style-type: none"> <li>- Support provided by physicians.</li> <li>- Stress and how to cope it.</li> <li>- Emotional problems.</li> <li>- Family problems.</li> <li>- How to deal with the loss.</li> <li>- Talking about feelings or fears.</li> <li>- More time for him/herself.</li> <li>- How to encounter other members of the family.</li> <li>- Manage and maintain relationships.</li> <li>- How to not get obsessed with the patient's disease.</li> <li>- Self-esteem.</li> <li>- Guilt.</li> <li>- Feeling overwhelmed.</li> <li>- Isolation.</li> <li>- Loneliness of caregiving.</li> <li>- Worry about the future, including the role as career.</li> </ul>
Physical needs	<ul style="list-style-type: none"> <li>- Fatigue.</li> <li>- Sleep problems.</li> <li>- Feeling like confinement due to their role.</li> <li>- Physical strain.</li> <li>- Maintain physical functioning.</li> <li>- Level of energy.</li> </ul>

	<ul style="list-style-type: none"> <li>- Caregiver burden (physical, emotional, social, and economic).</li> </ul>
Financial needs	<ul style="list-style-type: none"> <li>- Support to avoid missing work to provide care.</li> <li>- Financial assistance to avoid the use of savings or incurred debts.</li> </ul>
Social needs	<ul style="list-style-type: none"> <li>- Time for social activities.</li> <li>- Time for family activities.</li> <li>- Relationship with friends.</li> </ul>
Other needs related	<ul style="list-style-type: none"> <li>- Information about the medical condition and patient's health</li> <li>- More time with physicians</li> <li>- Reinforce the ability to cope with their role as caregivers.</li> <li>- Increase acceptance.</li> <li>- Increase self-efficacy.</li> <li>- Interrupted relationship with the patient.</li> <li>- Spiritual care.</li> <li>- More information about PC.</li> <li>- More support in symptom management, and decision-making.</li> <li>- Recognize and improve support for family caregivers.</li> <li>- End-of-life care and support for patients and caregivers.</li> <li>- Bereavement support.</li> <li>- More information about offered health care settings and services.</li> </ul>

**Table 4 Summarised health professional related needs of PC provision for older people**

Domains	Health professional related needs and factors
PC provision	<ul style="list-style-type: none"> <li>- Acknowledgement of PC</li> <li>- Further extension of PC among non-oncological patients.</li> <li>- Taking into consideration the biography of each patient.</li> <li>- Reduce the fear of being audited/judged.</li> <li>- Emotional support.</li> <li>- Decide how much information should be provided.</li> <li>- Reduce concern about asking personal questions to caregivers.</li> <li>- Communication with patients and their caregivers.</li> <li>- How to discuss life-sustaining measures with the patient.</li> <li>- A holistic approach to patient care, not only focused on physical symptoms.</li> <li>- More resources (particularly for people dying from conditions other than cancer).</li> <li>- Pay more attention to patients' wishes.</li> <li>- Early initiation of PC and involvement of PC teams.</li> <li>- Reduce the negative perception of PC, for instance by using other more accepted terms such as "Supportive Care".</li> <li>- More support from other professionals (clinical psychologists, social workers, psychiatrists).</li> <li>- More clarity on which service is responsible for bereavement care.</li> <li>- Reduce reticence to engage caregivers to address their emotional needs.</li> <li>- Formal discussions about how caregivers are coping with their situation.</li> <li>- Relevance of several skills such as empathy, respect, tolerance, ability to listen or patience.</li> <li>- Ability to make decisions, to improvise and to have the courage to deviate from standards in certain situations.</li> <li>- Formal assessments of bereavement instead of using only observation, intuition or informal chat.</li> <li>- Psychological assessment to screen for the likelihood of mental disorders.</li> <li>- Bereavement measures for post-death period.</li> </ul>

	<ul style="list-style-type: none"> <li>- Referral of patients to other services to provide appropriate bereavement support.</li> <li>- Knowledge about who to contact within case a patient need for PC.</li> <li>- Challenges inadequately controlling symptoms.</li> <li>- Higher interest in the components of PC.</li> <li>- Breaking understanding of PC as a defeat.</li> <li>- Consistent follow-up and dedicated staff member for post-death bereavement.</li> <li>- Assessment of caregivers' support needs during bereavement.</li> <li>- Face-to-face contact with bereaved caregivers at (PC) services.</li> <li>- Objective measures to identify caregivers at risk of poor bereavement.</li> <li>- More cooperation and experience with palliative home care (PHC) for professional caregivers.</li> <li>- Advance care planning in healthcare and PHC systems, and enhancing communication about care and PHC.</li> <li>- Additional palliative and end of life care education.</li> <li>- Need for a shared proactive multidisciplinary approach.</li> <li>- Multidisciplinary team meetings, personal notes and phone calls (extended professional networks).</li> </ul>
Training needs	<ul style="list-style-type: none"> <li>- Availability of specialized training in PC.</li> <li>- Higher education programmes at universities about PC.</li> <li>- Effects of drugs in the older population: unforeseeable interactions, side effects, or reduced compliance.</li> <li>- PC concept and possibilities.</li> </ul>

**Table 5 Summarised system related needs of PC provision for older people**

Domains	System related needs and factors
Institutional challenges/needs	<ul style="list-style-type: none"> <li>- More settings managing Palliative care</li> <li>- Clear systematization of palliative care</li> <li>- More respect to patients' rights and care preferences by Health and Safety regulations</li> <li>- Higher systematization between PC provision among complex chronic diseases</li> <li>- Connection between services (Multidisciplinarity and cooperation between professionals).</li> <li>- Institutional priorities including PC services.</li> <li>- Appropriate information about the components of PC.</li> <li>- More financial resources.</li> <li>- Improvement of working conditions of PC staff.</li> <li>- More key staff may mean availability to dispose more time to communicate with patients, families and other professionals.</li> <li>- Adequate infrastructures.</li> <li>- More integrated and continuity of care between health settings.</li> <li>- Less bureaucracy.</li> <li>- Where to have EOL discussions: emergency department, ICU or family physician's office; who should have EOL discussions.</li> <li>- Symptom assessment tools that were not validated in all patient groups.</li> <li>- Barriers to information logistics: Lack of widely shared electronic information systems or information transfer protocols.</li> <li>- External authority (policy makers, insurance companies and professional bodies) to support integrated palliative care practices across settings.</li> </ul>
Social challenges	<ul style="list-style-type: none"> <li>- Lack of knowledge about the implementation of PC in society.</li> <li>- Higher number of centres providing PC.</li> <li>- More awareness of the access to care among families.</li> <li>- More acceptance of the terminal period of life among families.</li> <li>- Cultural traditions and beliefs.</li> </ul>

	<ul style="list-style-type: none"> <li>- Breaking taboos about death within society.</li> <li>- PC services focused not only on patient care in the pre-death period; also in the caregiver during the post-death period.</li> <li>- Debate about the right place to die.</li> </ul>
Bereavement	<ul style="list-style-type: none"> <li>- Consistent follow-up and dedicated staff member for post-death bereavement.</li> <li>- Assessment of caregivers' support needs.</li> <li>- Face-to-face contact with bereaved caregivers at (PC) services.</li> <li>- Objective measures to identify caregivers at risk of poor bereavement.</li> </ul>



## 6 Discussion

### 6.1 Results of the review

This scoping review identified individual and contextual factors as well as facilitators and barriers to PC provision for older people living with multimorbidities. These identified needs were categorised based on different stakeholders and health system related factors. Patients expressed support needed on their emotional/mental health such as symptoms or experiences related to anxiety and depression, and support to address their clinical symptoms such as pain, fatigue and breathlessness. They also identified needs for practical support to maintain daily living and personal care, however they also expressed concerns about the potential burden that their needs may place on their families or caregivers and how these may interrupt their relationships. A number of facilitators were suggested by patients for PC provision, which highlighted the importance of patient-professional communications, PC education, easy access to services and the need for continuity of care. Needs identified in caregivers mirrored those identified by patients, but they emphasised bereavement support and financial support needed to care for both patients and themselves. Health professionals agreed that early intervention of PC was crucial, however some of them experienced difficulties in initiating the conversations with patients and/or families and recommended an alternative term such as “supportive care”. Integrated PC services were identified as desired care models, however concerns expressed with reference to resources (staff and time), training, and tools to assess the needs of patients and caregivers.

### 6.2 Strengths and weaknesses

A key strength of this review was the use of multiple sources of data enabling the InAdvance team to build on our existing understanding of PC needs in multimorbidities by identifying the range of support needs. High levels of symptom-based and emotional support were expressed by patients, and there seemed an increasing role for caregivers and health professionals as the disease progressed. A limitation of this review was that the included studies focused on patients with multimorbidities. Conclusion on needs or factors for each specific health condition could not be drawn. Therefore, careful interpretation is needed when aiming to understand PC needs in the management of different health conditions for older patients.

### 6.3 Conclusion

This review produced an initial summary on individual and contextual factors that impact on the PC needs in older patients with multimorbidities. Factors identified from this review are useful for the InAdvance project in understanding individual needs for PC provision in older patients with multimorbidities. Such needs and factors are also relevant to the development of the interview topic guide for WP3 – qualitative study to explore individual needs for the integration of PC in the management of chronic illnesses. These may also be important to partners

involved in this project who aim to develop interventions for supporting older people with multimorbidities. This review also calls for the development of a needs assessment tool (which the InAdvance will develop) to identify PC needs of patients and caregivers in a systematic manner, to enable the development of individualised integrated PC model for patients with complex PC needs.



## 7 References

1. WHO. *WHO Definition of Palliative Care*. [Online]. 2011. [Accessed 28th Aug]. Available from: <https://www.who.int/cancer/palliative/definition/en/>
2. Gardener, A.C., Ewing, G. and Farquhar, M. Enabling patients with advanced chronic obstructive pulmonary disease to identify and express their support needs to health care professionals: A qualitative study to develop a tool. *Palliative medicine*. 2019, **33**(6), pp.663-675.

