



Letters to the editor

Total pain in advanced dementia: a quick literature review

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Abstract

Objective: This quick literature review aimed to organize information on the detailed components of total pain in older people with advanced dementia in a holistic manner.

Materials and Methods: The authors analyzed qualitative data from relevant clinical guidelines or textbooks, focusing on certain types of pain and distress in older people with advanced dementia, followed by an expert panel review by research team members. In the search, the authors defined a person with advanced dementia as having a functional assessment staging tool scale score greater than or equal to six.

Results: The model covered a wide variety of pain, from physical pain to dementia-related psychological and spiritual aspects of total pain, including living environment change, stigma, discrimination, lack of communication and understanding, loss of sense of control and dignity, and cultural distress. It also identified physical appearance as an important factor in dying with dignity, as established by existing research on individuals with incurable cancers.

Conclusion: The conceptual model of total pain in people with advanced dementia is expected to help turn healthcare professionals' attention to physical, psychological, social, and spiritual contributors to total pain in advanced dementia.

Key words: palliative care, end-of-life care, total pain, dementia, dignity

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Introduction

Dame Cicely Saunders first articulated the theory of “total pain” to describe the sum of physical, psychological, social, and spiritual suffering experienced by patients with advanced diseases such as heart failure, respiratory failure,

and cancer¹). The theory suggests that the combination of and interplay between these elements results in a “total pain” experience that is individualized and specific to each patient’s particular situation²). Good pain management is a central pillar of good palliative care, and the assessment of total pain is a critical part of management. Without a clear conceptualization of total pain in patients with advanced diseases, the patient’s situation may not be accurately elicited²).

The importance of assessing and managing total pain in cancer patients has been widely recognized by both clinicians and researchers. However, cancer represents only a fraction of the serious diseases³). While current guidelines generally recommend palliative care for other diseases, such as heart failure, dementia, and chronic obstructive pulmonary disease, the assessment and management of total pain in patients dying from non-cancer causes has received limited focus. Consequently, a key question remains: Can

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the concept of total pain for cancer patients be translated to other patient populations?

Among non-cancer serious diseases, the palliative care needs of dementia patients have recently been recognized because it has been established over recent decades that the clinical course of advanced dementia, including uncomfortable symptoms such as pain, is similar to that experienced by older patients with cancer and other terminal conditions⁴). Furthermore, older people with dementia often feel confused, anxious, or frustrated, and the person-centered approach to dementia treatment uses positive reinforcement to meet their emotional needs and help them rediscover their identity^{4, 5}). Thus, the concept of total pain may provide a basis for palliative care need assessment to intervene successfully with people with advanced dementia.

A complete and thorough appreciation of all possible components of total pain is needed to apply the total pain theory to palliative care research and practice in advanced dementia. However, few studies have focused on the total pain experienced by older people with advanced dementia through a multidimensional lens. Therefore, this quick literature review aimed to organize information on the detailed components of total pain in older people with advanced dementia in a holistic manner.

Materials and Methods

The authors used a convenient sampling approach to obtain relevant information for synthesizing available clinical guidelines or textbooks focusing on certain types of pain and distress in older people with advanced dementia. Details of the relevant literature are presented in Table 1. A flow diagram of the study is shown in Figure 1. A brief search was performed on Amazon Books for all popular Japanese-published or English-Japanese translated books on palliative care for older people with advanced dementia available as of April 2021, regardless of the year of publication, using one or more of the following keywords: palliative care, end-of-life care, person-centered care, non-cancer, older person, and dementia. The titles and customer reviews of the retrieved books were screened for eligibility, and any books demonstrating components of total pain in people with advanced dementia were included. The authors also included an English textbook (Book No. 3) and two English guidelines (Books 8 and 12) for palliative care for older people, regardless of dementia. Finally, to enhance the search for spiritual aspects of total pain in older people with advanced dementia, the authors referred to the first author's (YH) previous papers on this topic.

The first author (YH), a geriatrician with extensive experience in qualitative research, extracted relevant information and identified key components of total pain in older people with advanced dementia through a manual bibliography

search, followed by an expert panel review by the research team members with dementia expertise, including the other authors (TY, SH, JO, MK, and HM). In the search, the authors defined a person with advanced dementia as having a functional assessment staging tool scale score greater than or equal to six. An inductive and deductive content analysis approach was used to organize the qualitative data into the concept of total pain⁶). The second author (TM), a healthcare communication designer, created an illustration to focus readers' attention on psychosocial and spiritual pain, as well as physical pain.

Results

The model produced from the component extraction results is illustrated in Figure 2. The model covered a wide variety of pain, from physical pain to dementia-related psychological and spiritual aspects of total pain, including living environment changes, stigma, discrimination, lack of communication and understanding, loss of sense of control and dignity, and cultural distress. It also identified physical appearance as an important factor associated with dying with dignity, as established by existing research on individuals with incurable cancer⁷).

Discussion

This qualitative review summarized the specifics of total pain in advanced dementia, and the authors revised the model of total pain in palliative care to apply it to advanced dementia patients. Pain is a subjective experience; however, with dementia, in contrast to cancer, patients' self-reported pain is limited. Pain in dementia patients must be translated by healthcare professionals into an objective assessment to guide interventions. This model reconfirmed that advanced dementia patients suffer symptoms including physical pain, breathlessness, and neuropsychiatric symptoms, as well as complications such as respiratory or urinary infections. It also provided a conceptual basis for actively reflecting on and evaluating the atmosphere and environment in care settings. Advanced dementia patients still have numerous complex physical, psychosocial, and spiritual needs requiring multidisciplinary health care. This model may help healthcare professionals identify and meet the unmet palliative care needs of dementia patients.

Conclusion

Dementia is the most common neurological disorder, usually chronic or progressive, leading to deterioration in cognitive function. It is a life-limiting condition; however, it is not recognized as a terminal disorder. Therefore, the authors revised the model of total pain in palliative care to

Table 1 Details of the analyzed literature analyzed

Book No.	Author/ Editor	Title	Literature category	Language	Publisher	Year of publication	ISBN/ASIN	Total number of pages
1	Benson S	The care assistant's guide to working with people with dementia	Textbook	English-Japanese translation	Tsutsui Shobo	2007	488720535X	269
2	Brooker D	Person-centered dementia care: making services better	Textbook	English-Japanese translation	Creates Kamogawa	2010	486342048X	242
3	Henderson ML, <i>et al.</i>	Improving nursing home care of the dying: a training manual for nursing home staff	Textbook	English	Springer Publishing	2003	826119255	208
4	Hirahara S & Kuwata M	Palliative care for dementia: end of life care for all	Textbook	Japanese	Nanzando	2019	4525381612	279
5	Hughes JC & Baldwin C	Ethical issues in dementia care: making difficult decisions	Textbook	English-Japanese translation	Creates Kamogawa	2017	4863421990	168
6	Kitwood T	Dementia reconsidered: The person comes first	Textbook	English-Japanese translation	Creates Kamogawa	2017	4863422075	272
7	Kitwood T & Bredin K	Person to Person: Guide to the care of those with failing mental powers	Textbook	English-Japanese translation	Bricolage	2018	4907946147	168
8	Kuebler KK, <i>et al.</i>	End of life care: Clinical practice guideline	Guideline	English	W.B. Saunders	2002	721684521	492
9	Kuwata M & Yuasa M	A practical guide to end of life care for older people (Vol. 1)	Textbook	Japanese	Chuohoki Publishing	2016	4805854006	215
10	Kuwata M & Yuasa M	A practical guide to end of life care for older people (Vol. 2)	Textbook	Japanese	Chuohoki Publishing	2016	4805854014	227
11	Loveday B	Leadership for person-centered dementia care	Textbook	English-Japanese translation	Community Life Support Center	2018	4904874609	159
12	Martin GA & Sabbagh MN	Palliative care for advanced Alzheimer's and dementia: guidelines and standards for evidence-based care	Guideline	English	Springer Publishing	2010	826106757	313
13	May H, <i>et al.</i>	Enriched care planning for people with dementia	Textbook	English-Japanese translation	Creates Kamogawa	2016	4863421745	264
14	Nagae H	Empathetic advance care planning: a practical guide for community-based networks of health care, medical and welfare professionals	Textbook	Japanese	Japanese Nursing Association Publishing	2018	4818021202	272
15	National Advisory Committee	A guide to end-of-life care for seniors	Guideline	English-Japanese translation	Kosei Kagaku Kenkyusho	2001	4905690781	273
16	Perrin T & May H	Wellbeing in dementia	Textbook	English-Japanese translation	Elsevier Japan	2007	4860348729	209
17	Robert Twycross R & Wilcock A	Introducing palliative care (fifth edition)	Textbook	English-Japanese translation	Igaku Shoin Medical Publishers	2018	4260035509	412

apply to advanced dementia patients. The conceptual model of total pain in people with advanced dementia may help turn healthcare professionals' attention to the physical, psychological, social, and spiritual contributors to total pain in advanced dementia.

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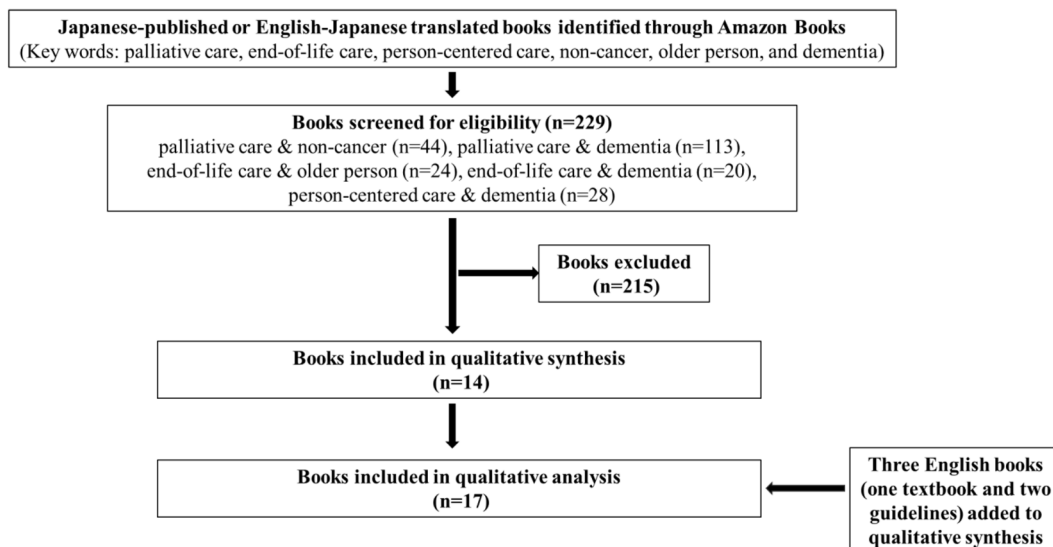


Figure 1 Study flow diagram.

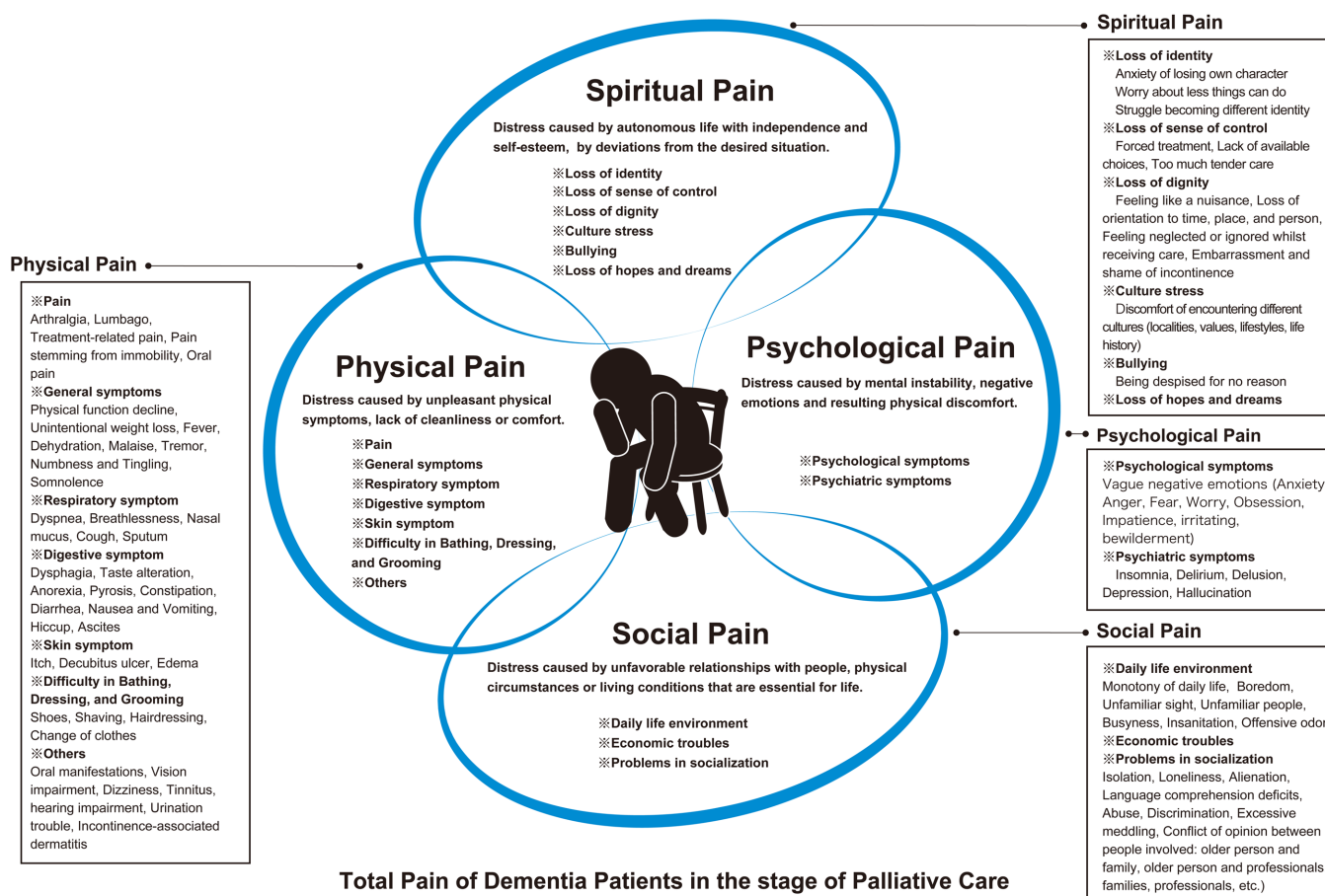


Figure 2 Total pain of dementia patients receiving palliative care.

Pain in advanced dementia can be understood as having physical, psychological, social, and spiritual components. Pain was not just a physical sensation: it might be a consequence of psychological and psychiatric symptoms, loneliness, spiritual distress, or daily life environment. The combination of these elements results in a “total pain” experience that is individualized and specific to each patient’s particular situation. Whether or not patients with advanced dementia report pain, hurting, or suffering, it is important to assess these experiences through a multidimensional lens that allows for the appreciation of all possible causes and influences.

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