

SUPPLEMENTARY FILES

Table 1. Search terms.

| |
|--|
| <p><u>1. Embase.com</u></p> <p>('advanced cancer'/de OR (((advance*) NEAR/4 (cancer* OR neoplas* OR carcinoma* OR tumor* OR tumour* OR malignan*))) :ab,ti OR ((Neoplasm/mj/exp OR 'cancer patient'/de OR (neoplas* OR cancer* OR carcinoma* OR oncolog* OR tumor* OR tumour* OR malignan*):ab,ti) AND ('metastasis'/exp OR 'palliative therapy'/exp OR 'palliative nursing'/de OR 'terminal care'/exp OR 'terminally ill patient'/exp OR (metasta* OR palliati* OR terminal* OR 'end of life' OR hospice* OR incurable*):ab,ti))) AND ('self care'/exp OR 'self monitoring'/de OR 'drug self administration'/de OR (((self) NEXT/1 (car* OR help* OR manag* OR medicat* OR treat* OR monitor* OR administrat*))) :ab,ti) NOT ('Conference Abstract'/it)</p> |
| <p><u>2. Medline Epub (Ovid)</u></p> <p>((((advance*) ADJ4 (cancer* OR neoplas* OR carcinoma* OR tumor* OR tumour* OR malignan*)):ab,ti. OR ((exp* Neoplasms/ OR (neoplas* OR cancer* OR carcinoma* OR oncolog* OR tumor* OR tumour* OR malignan*):ab,ti.) AND (exp "Neoplasm Metastasis"/ OR "Palliative Care"/ OR "Palliative Medicine"/ OR "Hospice and Palliative Care Nursing"/ OR exp "Terminal Care"/ OR "Terminally Ill"/ OR (metasta* OR palliati* OR terminal* OR ((end) ADJ2 (life)) OR hospice* OR incurable*):ab,ti.))) AND (exp "Self Care"/ OR (((self) ADJ (car* OR help* OR manag* OR medicat* OR treat* OR monitor* OR administrat*))) :ab,ti.)</p> |
| <p><u>3. PsycInfo (Ovid)</u></p> <p>((((advance*) ADJ4 (cancer* OR neoplas* OR carcinoma* OR tumor* OR tumour* OR malignan*)):ab,ti. OR ((exp* Neoplasms/ OR (neoplas* OR cancer* OR carcinoma* OR oncolog* OR tumor* OR tumour* OR malignan*):ab,ti.) AND ("Metastasis"/ OR "Terminal Cancer" OR exp "Death and Dying"/ OR "Palliative Care"/ OR "Hospice"/ OR "Terminally Ill Patients"/ OR (metasta* OR palliati* OR terminal* OR "end of life" OR hospice* OR incurable*):ab,ti.))) AND (exp "Self Management"/ OR "Self-Monitoring" OR (((self) ADJ (car* OR help* OR manag* OR medicat* OR treat* OR monitor* OR administrat*))) :ab,ti.)</p> |
| <p><u>4. Cochrane Central</u></p> <p>(((((advance*) NEAR/4 (cancer* OR neoplas* OR carcinoma* OR tumor* OR tumour* OR malignan*))) :ab,ti OR (((neoplas* OR cancer* OR carcinoma* OR oncolog* OR tumor* OR tumour* OR malignan*):ab,ti) AND ((metasta* OR palliati* OR terminal* OR 'end of life' OR hospice* OR incurable*):ab,ti))) AND (((self) NEXT/1 (car* OR help* OR manag* OR medicat* OR treat* OR monitor* OR administrat*))) :ab,ti)</p> |
| <p><u>5. Cinahl (EBSCO)</u></p> |

((advance*) N4 (cancer* OR neoplas* OR carcinoma* OR tumor* OR tumour* OR malignan*))
OR ((MM Neoplasms+ OR MH "Cancer Patients" OR (neoplas* OR cancer* OR carcinoma* OR
oncolog* OR tumor* OR tumour* OR malignan*)) AND (MH "Neoplasm Metastasis+" OR MH
"Hospice and Palliative Nursing+" OR MH "Terminal Care+" OR MH "Terminally Ill Patients+"
OR (metasta* OR palliati* OR terminal* OR "end of life" OR hospice* OR incurable*)))) AND
(MH "Self Care+" OR (((self) N1 (car* OR help* OR manag* OR medicat* OR treat* OR
monitor* OR administrat*)) OR (patient controlled N1 analgesi*)))

6. Web of Science

TS=((((advance*) NEAR/3 (cancer* OR neoplas* OR carcinoma* OR tumor* OR tumour* OR
malignan*)) OR (((neoplas* OR cancer* OR carcinoma* OR oncolog* OR tumor* OR tumour*
OR malignan*)) AND ((metasta* OR palliati* OR terminal* OR "end of life" OR hospice* OR
incurable*)))) AND (((self) NEAR/1 (car* OR help* OR manag* OR medicat* OR treat* OR
monitor* OR administrat*)))) AND DT=Article

7. Google Scholar

"advance|advanced|metastases|metastatic|palliative|terminally|"end of life"|hospice|incurable
cancer|neoplasm|neoplasms|carcinoma|tumor|tumour" "self
care|help|management|medication|treatment|monitoring|administration"

Table 2. **Non-experimental** qualitative study results on self-management strategies and corresponding experiences of patients with advanced cancer (23 studies)

| First author, year Patient population: type(s) of advanced cancer (N) | Self-management strategies and corresponding experiences | Self-management domains |
|---|---|--|
| Bennett, 2006 ⁴⁴ Breast cancer (N=8) | <ul style="list-style-type: none"> • Patients maintained daily activities to keep living in the present, although this was complicated by perceived physical and emotional constraints. • They used physical as well as emotional self-isolation to protect self, relatives and friends and/ or exert control. This also had negative consequences, e.g. anxiety about losing friends and support. | <ul style="list-style-type: none"> • Lifestyle • Social support |
| Campling, 2017 ³⁹ Various types, i.e.: bile duct, breast, colon, lung, and other (N=15) | <p>Medication management of patients approaching the end of life varied from full to no engagement: some patients accepted and preferred full responsibility in their medication management, whereas others limited their autonomy and decision-making. Patients adopted the following roles in medication management:</p> <ul style="list-style-type: none"> • Advocate, e.g. by requesting alternative opioids if side-effects were not acceptable; • Educator of relatives, anticipating future changes so that they could rely on relatives in case of worsening condition; • Facilitator, facilitating relationships with their healthcare professionals and relatives to aid access to their medicines; • Problem-solver, striving to navigate the difficulties posed by the medicines supply system and to problem-solve the side effects of their opioids, e.g. by titrating laxatives to offset the common side-effects. • Communicator of relevant information to relatives and healthcare professionals; • Goal-setter, self-planning or planning with a general practitioner or clinical nurse specialist; • Monitor, writing down of breakthrough doses and noting effectiveness; • Reporter of relevant symptom experiences and side effects. | <ul style="list-style-type: none"> • Medicine and pharmacology • Social support • Knowledge and information • Navigation and coordination • Medical decision-making |

| | | |
|---|--|--|
| | <p>The continual disease progression led to rapid changes in symptoms and side effects experienced by patients, which led to fluctuations in medication management roles and capabilities.</p> | |
| <p>Correa-Velez, 2005⁵²</p> <p>Various cancer types, i.e.: bladder, breast, gastrointestinal, lung, melanoma, ovarian, and prostate (N=39)</p> | <ul style="list-style-type: none"> • Patients used CAM for three main reasons, i.e. to: <ul style="list-style-type: none"> - control the cancer and prolong life; - relief cancer symptoms and side effects of conventional treatments; - detoxify the body, boost immunity, boost energy, and enhance quality of life. | <ul style="list-style-type: none"> • Lifestyle |
| <p>Devik, 2013⁶⁰</p> <p>Various cancer types; not specified (N=5)</p> | <p>To keep hope alive, cope with doubts and anxiety, and exert control, patients</p> <ul style="list-style-type: none"> • Underwent chemotherapy; • Maintained daily life, autonomy and independence as much as possible; • Focused on the positive sides and kept on dreaming. • They asked few questions, which resulted in a lack of knowledge and confusion concerning symptoms, disease progression and treatment. • Navigating through the healthcare system alone (e.g. ordering tests, arranging treatment schedules, and making practical plans) required much time and energy. Patients experienced limited control over practical arrangements (e.g. long waiting times for a bed, meal or taxi home). • Patients sought support from relatives and especially valued the emotional aspects of this support. They were reluctant to ask for assistance from relatives and healthcare professionals because of fears of becoming a burden and/ or a demanding patient. | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle • Psychology/ Mental health • Social support • Navigation and coordination |
| <p>Elliott, 2008⁴⁰</p> <p>Various cancer types, i.e.: breast, colorectal, kidney, lung, lymphoma, and other (N=28)</p> | <ul style="list-style-type: none"> • Patients used CAM because of a desire for cure, social reasons and improved quality of life through control over the disease and its side effects. They considered integrating it into conventional medicine. • Patients who did not use CAM framed it exclusively in terms of (unachievable) curative treatment. They perceived it as an affront to medical expertise and thought healthcare professionals would perceive it similarly. | <ul style="list-style-type: none"> • Lifestyle |

| | | |
|--|--|--|
| <p>Erol, 2018⁴¹</p> <p>Various cancer types, i.e.: colorectal, gastric, and lung (N=16)</p> | <p>Patients described pain at the end of life as an extremely difficult experience, which affected their daily life and social relations. They could not manage daily household chores and became dependent on their family members.</p> <p>Patients:</p> <ul style="list-style-type: none"> • Used non-pharmacological approaches to relieve pain, e.g. praying, changing position, having a hot bath, walking, watching TV, and engaging in crafts. Praying to God for healing and Namaz (an Islamic pray ritual) were the approaches most commonly used. Herbal product use was rare. • Generally avoided using pharmacological agents until the intensity of their pain increased and became unbearable. The most common problem was poor sleep; several patients used sleeping pills. • Less than half of the patients immediately informed the nurses about their pain and need for medication, others tried to be calm and patient, and informed healthcare professionals when the severity increased. | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle • Social support |
| <p>Gibbins, 2014⁶¹</p> <p>Various cancer types, i.e.: breast, lung, melanoma, mesothelioma, ovary, prostate, and sarcoma (N=12)</p> | <p>Self-management of pain was largely inspired by the wish to maintain role, self and independence. Patients</p> <ul style="list-style-type: none"> • Did not use pain medications as prescribed, but rather took the amounts perceived sufficient to 'keep a grip' on the pain without causing too many sedative side effects (which were considered a threat to self); • Tried to continue normal activities and everyday tasks (e.g. household chores, hobbies); • Adjusted activities to pain; • Adjusted expectations from becoming pain free to alleviating pain; • Sought help from others, but only when normal activities were threatened. Patients considered maintaining relationships important, but difficult due to discomfort caused by physical dependence and seeing relatives distressed by their pain. They found it challenging to communicate pain to healthcare professionals due to a perceived lack of interest from healthcare professionals. • Patients considered knowledge about causes of pain even more important than pain relief (possibly due to fear of disease progression). | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle • Psychology/ Mental health • Social support • Knowledge and information |
| <p>Hansen, 2015⁴⁹</p> <p>Hepatocellular cancer (N=14)</p> | <ul style="list-style-type: none"> • Patients searched alternative sources (i.e. internet, books and friends) for information. • They compared their cancer to other diseases and examined changes in physical condition to understand and describe their disease. | <ul style="list-style-type: none"> • Medicine and pharmacology |

| | | |
|--|---|---|
| | <ul style="list-style-type: none"> • Patients started medical treatments because these provided a sense of control. Over time, they more often decided to stop or refuse (additional) treatments and/ or regretted having ever started treatments because of adverse side effects, uncertainty about treatment efficacy and an increased focus on quality of life. | <ul style="list-style-type: none"> • Knowledge and information • Medical decision-making |
| <p>Hopkinson, 2007⁵⁴</p> <p>Various cancer types, i.e.: breast, gastrointestinal, head and neck, lung, prostate, and other (N=30)</p> | <ul style="list-style-type: none"> • Patients ate nutritious, tolerable food to retain a sense of control over changing eating habits. • They also ate to please relatives. | <ul style="list-style-type: none"> • Lifestyle |
| <p>Johansson, 2006⁶²</p> <p>Various cancer types, i.e.: bile duct, bladder, breast, and prostate (N=5)</p> | <p>Patients highly valued ordinariness and found it important to live their lives more or less as they did before they became ill. They</p> <ul style="list-style-type: none"> • Took extra drug doses in case of breakthrough pain; • Balanced rest and physical activity to alleviate suffering; • Maintained daily activities; • Kept positive memories alive and increased other positive coping skills; • Kept occupied with tasks and being important to others. Emotional support from relatives and friends was considered essential and provided distraction. Support from healthcare professionals was perceived as positive, committed and testifying to control over the situation, which gave a sense of security. • Patients prepared themselves and their relatives for how they wanted things to be after their death; • They independently took important decisions about their present lives and the future. They still had a clear mind to do this. | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle • Psychology/ Mental health • Social support • Navigation and coordination • Medical decision-making |
| <p>Johnston, 2012⁵⁵</p> <p>Various cancer types, i.e.: breast, colorectal,</p> | <ul style="list-style-type: none"> • Patients tried to wash, dress, shop and cook themselves. They wanted to be seen as normal and not as an illness. • They used CAM. This was considered a beneficial strategy mainly by patients who lived in urban areas or attended in hospice day care. | <ul style="list-style-type: none"> • Lifestyle • Psychology/ Mental health • Social support |

| | | |
|---|---|--|
| gastrointestinal, hematological, lung, and urogenital (N=20) | <ul style="list-style-type: none"> • Patients practised religion. • They focused on acceptance, positivity, and their rights of choice and control. • They sought support from other cancer patients. Sometimes they received support from a clinical nurse specialist; only few patients received care to stay at home. They wanted to stay at home. • They sorted out affairs, planned their funeral and/ or discussed what to expect and how to prepare for death. Healthcare professionals were only rarely involved in these discussions. | <ul style="list-style-type: none"> • Navigation and coordination |
| La Cour, 2009 ⁵⁹ Various cancer types, i.e.: breast, colon, lung (N=45) | <ul style="list-style-type: none"> • Patients maintained their daily activities by avoiding activities that might cause them pain or harm. • They undertook novel activities to enrich their daily routine. • Patients limited social networks to relatives and close friends. They did not want to be a burden to their relatives and friends. They expressed a desire to be with others with the same condition, but were also concerned that this would lead to too much talking about the disease. | <ul style="list-style-type: none"> • Lifestyle • Social support |
| Levy, 2015 ⁴⁸ Prostate cancer (N=5) | <ul style="list-style-type: none"> • Patients did new and familiar leisure activities to live in the present and be distracted from pain. • Patients did meaningful activities, such as volunteering, to renegotiate their sense of who they were. The benefits of new activities gave them a sense of belonging and connection, which counteracted the feelings of separation that their 'between life and death' state entailed. They channelled thoughts of their own death towards their family's future well-being and tried to maintain their role as head of the family even after death, thereby enhancing this role in the present. These strategies were sometimes incompatible, causing psychological turmoil. • Patients socialised and spent time with relatives. They took control of communication with relatives about their cancer and impending death. • Patients looked for information about treatment. • They made financial and practical plans to control their death. • They strove to move forward in a goal-oriented and active way, by using short-term goals ('stepping stones') as bridges between time and achievement of life purposes. | <ul style="list-style-type: none"> • Lifestyle • Psychology/ Mental health • Social support • Knowledge and information • Navigation and coordination • Medical decision-making |
| Lewis, 2016 ⁴⁵ Breast cancer (N=18) | <p>Three self-management styles:</p> <p>1) Patients who strove for normality</p> | <ul style="list-style-type: none"> • Lifestyle • Psychology/ Mental health |

| | | |
|--|---|--|
| | <ul style="list-style-type: none"> • These patients did not make any major lifestyle changes because continuing life as it used to be was so important to them. • They tried to minimize the negative social impacts of having metastatic disease. • They tried not to think, talk or read about their cancer to live in the present, exert control over their disease experience and protect themselves from feelings of unhappiness. <p>2) Patients who re-evaluated life</p> <ul style="list-style-type: none"> • These patients re-evaluated what was most important to them. A positive mind-set contributed to keeping control over their disease. • They devoted more time with relatives and friends. The emotional support received by talking with relatives and friends was of great importance. <p>3) Patients who felt restricted</p> <ul style="list-style-type: none"> • These patients described lifestyle strategies that were continuously changing because their health was so variable. Although they tried to get on, they felt limited by disease symptoms and side effects of treatment. | <ul style="list-style-type: none"> • Social support • Knowledge and information |
| <p>Liu, 2017⁴²</p> <p>Various cancer types, i.e.: breast, lung, pancreatic, prostate, and other (N=9)</p> | <p>Patients described that breakthrough cancer pain adversely affected daily activities, sleep, and feelings; they could not eat, walk, and run. Sometimes pain even caused extreme difficulties with sitting down and getting up. Patients</p> <ul style="list-style-type: none"> • Endured their pain, because this is encouraged by the traditional Chinese culture, in which pain is part of the disease process, and because they did not want to be labelled as hypochondriacs or complainers. • Used massage, acupuncture, and other non-pharmacological pain management methods. • Took nonsteroidal anti-inflammatory medicines or visited pain clinic doctors when they felt that these medicines were ineffective. • Sought support from the healthcare system to understand and control breakthrough pain and to communicate effectively with healthcare professionals. | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle • Psychology / Mental health • Knowledge and information • Navigation and coordination |
| <p>McPherson, 2014⁶³</p> <p>Various cancer types, i.e.: breast,</p> | <p>Patients had a strong desire to be independent in their pain management. They often</p> <ul style="list-style-type: none"> • Rejected pharmacological approaches because of the side effects; • Delayed or omitted their medication intake and endured pain; | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle |

| | | |
|--|--|---|
| gastrointestinal, respiratory/thoracic, urogenital, and other (N=18) | <ul style="list-style-type: none"> • Tried to relief pain with non-pharmacological approaches, such as lying down, sleeping, changing position, not moving and distraction. • Patients sought support from others, but only mentioned their pain when it became too difficult to manage. They did not always relatives in discussions with professional caregivers visiting them at home, also because did not want to bother their relatives. • Patients sometimes delegated roles in in pain control (e.g. deciding on pain treatment approach, taking responsibility for obtaining medications and attending appointments) to their relatives (depending on their physical and psychological functioning). | <ul style="list-style-type: none"> • Social support • Navigation and coordination |
| Pacsi, 2015 ⁴⁶ Breast cancer (N=6) | <ul style="list-style-type: none"> • Patients made extensive dietary changes. • They emphasised the power of prayer, which gave the strength to deal with the treatment and its side effects while focusing on living in the moment. • They adjusted to changes in body image. • They promoted breast cancer awareness. • They maintained a positive attitude. • They tried to participate actively in their children's lives. • Patients made informed decisions about the treatments. | <ul style="list-style-type: none"> • Lifestyle • Psychology/ Mental health • Social support • Medical decision-making |
| Peoples, 2017 ⁶⁶ Various cancer types, i.e.: breast, cervix, colon, lung, prostate, and other (N=73) | <p>To manage daily activities, patients:</p> <ul style="list-style-type: none"> • Took breaks during the day or divided activities into smaller parts; • Sometimes asked for assistance from others (mostly relatives, friends and neighbours) to manage their activities, required social services, and/ or used assistive devices; • Limited their social interactions to close friends and relatives; • Set short-term goals to fulfil wishes and reach long-term goals. | <ul style="list-style-type: none"> • Lifestyle • Social support • Medical decision-making |
| Sand, 2009 ⁵¹ Various cancer types, i.e.: breast, | <p>To manage and remain in control over medication intake, patients:</p> <ul style="list-style-type: none"> • Questioned whether they actually needed prescribed medication; • Discontinued or titrated the amount of medication; | <ul style="list-style-type: none"> • Medicine and pharmacology • Social support |

| | | |
|--|---|---|
| gastrointestinal, lung, melanoma, and urogenital (N=15) | <ul style="list-style-type: none"> • Sometimes delayed medication intake until they were no longer able to hold the pain. • Patients with self-regulation problems let their relatives take over the responsibility for their medication. Support from others was considered helpful. Patients wanted healthcare professionals to listen better. • They wanted to be informed about the side effects and importance of their medication and the time it would take to reach the maximum dosage. Some patients wondered whether better medicines might have come available and why they had not received palliative medication earlier. | <ul style="list-style-type: none"> • Knowledge and information • Navigation and coordination |
| Schulman-Green, 2011 ⁴⁷ Breast cancer (N=15) | <ul style="list-style-type: none"> • Patients adhered to treatment regimens. • They engaged in exercise and nutritional regimens. • They kept life as normal as possible. • They sought support from friends and relatives and evaluated and ensured support at home. • They learned about cancer. • They coordinated medical services. • They participated in advance care planning. • They made treatment decisions. <p>They reported barriers of symptom distress, limited time and energy, competing priorities, lack of understanding of the different forms of care, and fears to make the right decisions.</p> | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle • Social support • Knowledge and information • Navigation and coordination • Medical decision-making |
| Stephens, 2014 ⁵⁰ Myeloma (N=11) | <ul style="list-style-type: none"> • Patients manipulated medication schedules to manage the side effects of treatment. • They tried to get an adequate fluid-intake, made dietary changes and exercised to rebuild strength and reduce complications. • They gathered information about their disease. • They rather let primary support persons (usually a partner or child) make disclosures on diagnosis or disease progression to other family members to manage their distressing emotions. | <ul style="list-style-type: none"> • Medicine and pharmacology • Lifestyle • Knowledge and information • Social support |
| Thomas, 1999 ⁶⁵ Various cancer types; not specified (N=19) | <ul style="list-style-type: none"> • Patients adopted one or more CAM treatments. • They reached out to a wide-ranging network of relatives, friends and other support systems, but found it difficult to accept the encouragement and positivity. Patients perceived their healthcare professionals as supportive, but | <ul style="list-style-type: none"> • Lifestyle • Social support |

| | | |
|--|--|--|
| | <p>others felt that healthcare professionals ignored their emotional needs. They mentioned that listening to others with cancer helped them to understand their disease better.</p> <ul style="list-style-type: none"> • Patients wanted to know more about their cancer. • They weighed up options, made choices, participated in decisions affecting themselves and others, set goals, and gauged future outcomes. | <ul style="list-style-type: none"> • Knowledge and information • Medical decision-making |
|--|--|--|

CAM: Complementary and alternative medicine