



---

2020

## A systems thinking framework to improve care of the terminally ill: An Australian case study

Elizabeth Summerfield

University of Melbourne, [elizabeth.summerfield@unimelb.edu.au](mailto:elizabeth.summerfield@unimelb.edu.au)

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Communication Commons](#), [Curriculum and Instruction Commons](#), [Educational Methods Commons](#), [Health Services Research Commons](#), and the [Leadership Studies Commons](#)

---

### Recommended Citation

Summerfield, Elizabeth (2020) "A systems thinking framework to improve care of the terminally ill: An Australian case study," *Patient Experience Journal*: Vol. 7 : Iss. 3 , Article 27.

DOI: [10.35680/2372-0247.1419](https://doi.org/10.35680/2372-0247.1419)

This Case Study is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

---

## **A systems thinking framework to improve care of the terminally ill: An Australian case study**

### **Cover Page Footnote**

This article is associated with the Culture & Leadership lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_CultureLeadership](http://bit.ly/PX_CultureLeadership)

# A systems thinking framework to improve care of the terminally ill: An Australian case study

Elizabeth Summerfield, *University of Melbourne, elizabeth.summerfield@unimelb.edu.au*

## Abstract

This paper argues the value of systems thinking to patients, family members and medical practitioners in end-of-life care, particularly as a mechanism for considering when palliative care should be introduced as preferred treatment. It applies a well-established set of tenets in systems thinking retrospectively to a case study of patient care in Australia. This highlights how and where different decisions might have been made, based on a holistic consideration of the patient's best interests. The case is written from the perspective of a family caregiver. It argues that early, deliberate conversation, framed by systems thinking tenets, can support the call for the more timely intervention of palliative care. As a precursor to effective conversation, the case supports recent calls for increased training in systems thinking in graduate and continuing medical education. A change in medical practice would both facilitate and be enabled by a broader cultural change in public attitudes toward dying, end-of-life care and death. Encouraging the documentation of single case studies, written or co-written by medical practitioners and family carers can contribute to the evidence base of both medical and public education.

## Keywords

Palliative care, systems thinking, terminal illness, medical education, public education

## Introduction

This case offers the perspective of a family caregiver as participant researcher. It highlights two problems of medical practice and knowledge in the care of the terminally ill cancer patient: the need to improve the place palliative care occupies in the minds of the medical practitioners and the family carers involved; and the value of a deeper knowledge and practice of systems thinking in considerations of end-of-life care. It argues for the early introduction of palliative care when the patient's wish is to live as high quality, and pain-free life as possible.

## Palliative Care

Common barriers to the use of palliative care as a first-line treatment by physicians are well documented. These include the view that it should only be used if curative treatment fails; that it can be provided by any physician, whatever their speciality; that it signifies the end of hope to the patient and failure by the physician; and that many physicians remain unaware of its availability or benefits. Resistance, or a lack of knowledge, also occurs in the community at-large. A cultural reluctance to discuss dying and death as inevitable components of life, and the role family members and palliative care professionals can play together in supporting death, affects both physicians and lay people alike.<sup>1-6</sup>

Palliative care is defined by the Center to Advance Palliative Care as:

specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness— whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.<sup>7</sup>

Such care has been demonstrated to assist patients and their families to manage symptom burden, psychosocial needs, spiritual well-being, existential issues, treatment decision-making, and end-of-life scenarios.

## International Differences in Barriers to Palliative Care

Research indicates that there may be national differences in the active engagement of palliative care specialists by oncologists. For example, a greater level of acceptance and engagement has been identified in the United States compared to the United Kingdom.<sup>8</sup> In 2018, research in the latter noted that patients continued to receive anticancer treatment, without information that this may not enhance survival, and with the possibility that the cumulative side effects of treatment could negatively impact the quality of the patient's remaining life.<sup>9</sup> The option of palliative care was not offered.

But even in the U.S., there remains a need for advocacy in oncology practice of palliative care. As recently as 2019, researchers noted the perception by patients and their families that palliative care consultations continued to be offered too late.<sup>10</sup> In 2017, Back had noted the changing U.S. culture in oncology practice where palliative care peers were being engaged less as a final resort. But he argued more needed to be done. He advocated increased medical education in communication skills as a solution. Such training would enable physicians to conduct conversations with patients and families about goals of care early in the diagnostic process. A fundamental impediment to this is traditional medical epistemology. He noted that the ‘usual model of learning in oncology is a conduit model—knowledge is a kind of object that is transferred from teacher to student’.<sup>11</sup> In other words, the focus of instruction was on transmission of established factual detail of disease and its treatment, rather than on situating disease within the big picture of an individual’s physical, emotional, mental and spiritual health.

## Systems Thinking

Other medical educators argue the need for a greater role of systems thinking in graduate and continuing medical training, noting its demonstrable benefits to other professions where problem-solving of highly complex issues is also demanded.<sup>12-15</sup> Colbert and Ogden et al. offer the following simple definition of systems thinking as they advocate its greater role in graduate medical training:

Systems thinking is defined as the ability to analyze systems as a whole.

Systems thinking, as a field of leadership education, has evolved over a half century following its conception at M.I.T.<sup>16</sup> It is a style of thinking that leading scholars in the field argue was lost as the Industrial and Scientific Revolutions of the nineteenth century defined learning and research in the twentieth century. Technological, commercial and educational knowledge and practice became increasingly fragmented as specialist knowledge of the parts of a whole grew.<sup>17</sup> Medical knowledge and including the medicalization of dying and death were part of this trend.

This paper links the call for improved use of palliative care in terminally ill cancer patients, to that of increased education in systems thinking in the medical profession, as well as the larger community. It uses a set of systems thinking tenets as a framework for reconsidering how this may have improved the trajectory of care for an Australian patient and her family.

## Method

The author has written this article as a piece of action research from the perspective of principle family carer during my mother’s final months of life. She died at home on 2 May 2019 from the impact of sacral metastases, following an initial diagnosis of stage 3 breast cancer 2.5 years earlier. With the active support of my sister and brother-in-law and teamed with two Palliative Care nurses and a PC nurse practitioner, we cared for Mum at home for the final four weeks of her life.

The systems thinking framework, applied retrospectively to the narrative of treatment and care, is that defined in the seminal text, *The Fifth Discipline*, by leading scholar and practitioner of systems thinking, Peter Senge. The tenets of the framework, with a brief description, are as follows:

- **Personal mastery**  
This requires each participant involved in decision-making to be clear about their personal goals for care, to strive to see clearly the objective reality of what is happening, and to be patient in thinking and discussing the above.
- **Mental models**  
This requires participants to identify and articulate their own deeply held assumptions about care and how it is to be achieved.
- **Building shared vision**  
This requires the development of a shared picture for the progression of care.
- **Team learning**  
This requires a deliberate conversation that enables participants to empathise with the assumptions and perspectives of others involved and to genuinely consider together how best to move forward.
- **Systems thinking**  
This requires the integration of the above tenets to enable the emergence of the big picture of care, rather than a focus on or prioritising of one or more of its parts.<sup>18</sup>

Following the outline of the diagnosis, treatment and care of the patient that follows, the above tenets will be applied to that trajectory to suggest one alternative set of decisions which would have improved the end-of-life care of the patient.

## Narrative Case Study

In June 2016 my mother, then 88, was diagnosed with Stage 3 breast cancer. A partial mastectomy was followed by a course of radiotherapy. In January 2019 persistent lower back pain was initially diagnosed by the General Practitioner (GP) as sciatica and later found to be Stage 4 breast cancer. Referral was made by the Neurosurgeon back to the treating Radiation Oncologist (RO). A biopsy of the sacral tumour eliminated the possibility of a second primary. A ten-day course of radiotherapy was then prescribed. When the first treatment resulted in partial immobility, the author wrote to the RO declaring my mother's wish not to undergo painful treatment but to live as high a quality of life as possible. The RO agreed but treatment continued alongside increasing immobility, exceptional pain and significantly decreasing quality of life. The RO requested a Palliative Care consultation only after the failure of radiation and my mother's refusal of chemotherapy. The family assumed oversight of her care for the remaining four weeks of her life at her home, supported by Palliative Care professionals.

Table 1 (Appendix) outlines chronologically the key elements of the narrative of diagnosis and care.

## Lessons Learned: Applying Systems Thinking Framework

The shock of a terminal diagnosis and the sense of urgency to act, coupled with a healthcare system with a focus on curing disease through interventionist treatment, and a cultural assumption that end-of-life care ought to be managed medically, all leads to the unreflective momentum of events that marked my mother's trajectory towards an unnecessarily painful death.

But, if the systems thinking tenets, outlined earlier, had framed the decision-making of each of the actors instead, a more profound experience may have resulted. This would have allowed for a better balance of the physical, emotional and spiritual dimensions of the dying process, rather than have these elements determined by the singular focus on the physical.

## Alternative Decisions

The final, synthesizing tenet of Senge's framework 'systems thinking', seeks 'to enable the emergence of the big picture of care, rather than a focus on or prioritising of one or more of its parts'. Applied to my mother's care, this would have meant pausing at the point of discovery of the sacral metastases by the Neurosurgeon. The Neurosurgeon, recognizing the initial misdiagnosis of sciatica by the GP, would have referred my mother back to her. The GP had overseen her physical, mental and emotional health for decades. With that deep knowledge

of the whole human being, she could have facilitated an inclusive discussion about my mother's wishes for end-of-life care, in consultation with the relevant oncologists and palliative care physicians, and their specialist knowledge of the risks and benefits associated with each possible intervention. Time could have been taken by my mother and her family to consider these carefully, allowing for her much greater control of her own end-of-life. Armed with the knowledge of the potential risk of severe pain induced first by the biopsy, and then by the radiation, and the option of immediate introduction of palliative care, her choice would have been the latter.

The realization of this alternative, more humane scenario depended on an awareness and application of the first tenets of Senge's framework - 'personal mastery' and 'mental models' - by each of the medical and family actors. Instead the unarticulated, shared assumption was that the discovery of the metastases demanded the treatment of the disease as soon as possible by a specialist trained to do that. This focus on bodily malfunction ignored not only the possibility of doing even further damage, but the mental, emotional and spiritual needs of the patient and her family. The relevant 'personal mastery' was assumed by all to belong to the Radiation Oncologist. She alone had the training to treat the disease. 'Building a shared vision' was ignored because the disease was fore-fronted rather than the more profound reality of the end-of-life. A clear acknowledgement and articulation of the latter by all actors would have been the catalyst for the activation of each of the tenets of Senge's systems thinking framework. Its absence, until it could no longer be ignored, is an unfortunate reflection of the medical profession's absorption of a larger, continuing societal discomfort with death and dying.

Table 2 (Appendix) below outlines patient- rather than disease-centered alternative decisions to the actual care trajectory, mapped to Senge's systems thinking tenets.

The fourth and fifth tenets of 'team learning' and 'systems thinking', were exercised in a limited way once palliative care was enlisted as a last resort and my mother's quality of life had been significantly compromised.

The overarching lesson learned was the inability of the actors to frame and articulate the whole picture of patient care. Family members were a constant presence, but lacked the medical knowledge to critically assess decision-making, and deferred to the series of clinicians in distressing circumstances of constant change. Medical professionals exercised roles defined by deference to escalating specialist care of the diseased part of the patient.

This sad trajectory is described in Atul Gawande's book *Being Mortal*.<sup>19</sup> As a medical specialist, former policy advisor and family carer, he documents his father's end-of-

life journey following a cancer diagnosis. He argues for a greater 'interpretive' role by doctors in the care of terminal illness. This would replace the traditional paternalism of the doctor-patient relationship, in which responsibility for care is tacitly assumed by the relevant medical specialist and deferred by patient and carers. The interpretive model is instead one of facilitation, providing the necessary clinical information, but enabling the patient's deepest needs for holistic care to be the guide to final decision-making.

### **Palliative Care: Systemic Thought & Practice**

Systems thinking, defined as 'the ability to analyze systems as a whole,' offers an accessible framework for thinking by medical practitioners, patients and family alike to consider the quality of end-of-life care, and to help promote a more prominent role for palliative care than it generally occupies.

In healthcare systems, the principal question raised by this case study is: who is best placed to facilitate a conversation that can integrate vital medical information with other critical information, i.e. the patient's emotional, psychological and spiritual needs, in cases of terminal illness in order to determine their best possible end-of-life experience?

The questions for the patients and/or their family when they receive a diagnosis of terminal illness are: what is most critical to me at this stage of my life? Do I/we have the mental, emotional, psychological and physical stamina to participate actively in the complexities of care in my/her/his dying and death?

In the medical system of specialist care, the answer to the first question is either the GP or Palliative Care specialist. Each has both a broad understanding of the medical information and an appreciation of the patient as a whole human being.

Regretfully, in our present culture, medicalization of the management of death and dying through a focus on disease is the default position, and so the second question is rarely formulated by patient and family.

### **Discussion: Practice Implications and Recommendations**

This case study supports the call for improved medical education to enable deliberate and difficult discussion of terminal illness and end-of-life care with patients and their families. Training in skills, that promote the view of terminal illness and its management in more systemic ways, could be enhanced by access to case studies written from both medical and lay perspectives. Such cases help to render abstract epistemological concepts like systems

thinking much more concrete through application to particular set/s of circumstances. Such training sits at odds with increasing medical specialization, but need not if a regard for the whole human being becomes the central principle of treatment and care.

Changes to broad, cultural thinking about dying, death and shared responsibility for the provision of end-of-life care by patients and family members will complement and accelerate a shift in medical education and practice. Publications written and co-written by medical practitioners, patients and carers for an educated, generalist audience, have the capacity to influence change in both professional and lay audiences, and reduce the prevailing fear and silence surrounding dying and death. The latter only serves to reinforce the medical model of dying and death and place the entire burden on to specialist healthcare professionals. It also creates distance not intimacy between family members in the false hope of avoiding the trauma of loss. In doing so it denies patients, family and GPs the opportunity to cushion loss through the provision of intense mutual support and care.

In summary, this Australian case study contributes evidence to the argument for a reversal of the increasingly specialized and humanly fragmented medical trajectory of treatment and care, and the broader cultural view of dying and death, which enables its perpetuation.

### **Limitations and Further Research**

This case study offers evidence from a non-medical perspective to support an existing call for systems thinking in medical training and practice in order to promote the early introduction of palliative care in terminally ill patients. But there are limits to a single case study written by a researcher intimately involved in the care of her mother. The inability to generalize from the experience of an individual patient in a single country is one. The possibility of bias or misperception by the researcher in circumstances of intense emotional investment is another.

The validity of generalization and the argument for change depends on further documentation of single case studies viewed from multiple perspectives: general and specialist practitioners, palliative care staff, patients, where possible, their carers and family members.<sup>20</sup> These, and others, make up the complete system of healthcare. The integration of each part of this system has the potential to provide the whole picture of the most humane treatment and care of the dying at this most critical stage in their and their family's lives. Multiple voices and perspectives could be integrated in a meta-analysis mapped to the five tenets of Senge's framework.

## Conclusion

This case study has offered a patient and family carer perspective of the medical management of end-of-life care. It contributes a voice to the argument that palliative care expertise should be introduced much earlier in the process. It does so by outlining a framework for thinking about such care holistically, both in terms of the multiple actors involved, and of a shared mindset that each can bring to deliberations. In the present medical model of end-of-life care, which can involve multiple medical and lay actors, it argues that responsibility for integrating the big picture of care is best done by palliative care specialists and general practitioners trained to consider both medical and humanist perspectives. A shared systems thinking framework offers an enabling tool to do so.

## References

- Berry, L, Castellani, R, Stuart, B, 'The Branding of Palliative Care', *Journal of Oncology Practice*, 2016, 12, 1: 48-53;
- Cicoello, K, Anandarajah, G, 'Multiple Stakeholders' Perspectives Regarding Barriers to Hospice Enrollment in Diverse Patient Populations: A Qualitative Study', *Journal of Pain and Symptom Management*, 2019, 57, 5: 869-879;
- Kaufmann, T, and Kamal, A, 'Oncology and Palliative Care Integration: Cocreating Quality and Value in the Era of Health Care Reform', *Journal of Oncology Practice*, 2017, 13, 9: 580-588;
- Schlick, C, and Bentrem, D, 'Timing of palliative care: When to call for a palliative care consult', *Journal of Surgical Oncology*, 2019, 120: 30-34;
- Bakitas, M, El-Jawahri, A, Farquhar, M, Ferrell, B, Gradzen, C, Higginson, I, Temel, J, Zimmermann, C, and Smith, T, 2017, 'The TEAM Approach to Improving Oncology Outcomes by Incorporating Palliative Care in Practice', *Journal of Oncology Practice*, 13, 9: 557-567;
- Ziegler, L, 'Not enough cancer patients are getting end of life care – new study', *The Conversation*, 2018, <https://theconversation.com/not-enough-cancer-patients-are-getting-end-of-life-care-new-study-90720>. Accessed June 2019.
- Nicolich, M, El-Jawahri, A, Temel, J, LeBlanc, T, *Discussing the Evidence for Upstream Palliative Care in Improving Outcomes in Advanced Cancer*, ASCO Educational Book, 2016: <https://ascopubs.org/action/doSearch?SeriesKey=edb&AllField=%2C+Discussing+the+Evidence+for+Upstream+Palliative+Care+in+Improving+Outcomes+in+Advanced+Cancer%2C&ConceptID=>, accessed October 2019.
- American Society of Clinical Oncology, JCO Oncology Practice's Special Issue on Palliative Care, 2017, 13, 9: <https://ascopubs.org/toc/jop/13/9>, accessed September 2019.
- Ziegler, L, Craigs, C, West R, Carder P, Hurlow, A, Millares-Martin, P, Hall, G, Bennett, M, 'Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study' *BMJ Open*, 2018; <https://theconversation.com/not-enough-cancer-patients-are-getting-end-of-life-care-new-study-90720>
- Cicoello, K. and Gowri, A, Multiple Stakeholders' Perspectives Regarding Barriers to Hospice Enrollment in Diverse Patient Populations: A Qualitative Study, *Journal of Pain and Symptom Management*, 2019, May; 57, 5, 869-79.
- Back, A., 'What Enables Oncologists to Discuss Goals of Care With Their Patients? Practical Ways Toward a Culture of Kindness, Transparency, and Responsibility', *Journal of Oncology Practice*, 2017, 13, 9: 591-93.
- Plack, M, Goldman, E, Scott, A, Pintz, C, Herrmann, K, Thompson, T, Brundage, S, 'Systems Thinking and Systems-Based Practice Across the health Professions; An Inquiry into Definitions, Teaching Practices, and Assessment', *Teaching and Learning in Medicine*, 2018, 30, 3: 242-54.
- Bordage, G, 'Conceptual Frameworks to Illuminate and Magnify', *Medical Education*, 2009, 43: 312-19.
- Wilkinson, J, Goff, M, Rusoja, E, Hanson, C. and Swanson, R, 'The Application of Systems Thinking Concepts, Methods and Tools to Global Health Practices: An Analysis of Case Studies', *Journal of Evaluation in Clinical Practice*, 2018, 24, 3: 607-618.
- Colbert, C, Ogden, P, Ownby, A. and Bowe, C, 'Systems-Based Practice in Graduate Medical Education: Systems Thinking as the Missing Foundational Construct', *Teaching and Learning in Medicine*, 2011, 23, 2: 179–185.
- Forrester, J., *Principles of Systems*, MIT Press, MA, 1968.
- Meadows, D., *Thinking in Systems: A Primer*, 2009, Earthscan, London.
- Senge, P., *Fifth Discipline: The Art and Practice of the Learning Organization*, 2006, Doubleday, New York, p. 8.
- Gawande, A. *Being Mortal*, 2015, Profile Books Ltd, London, pp. 200-201.
- Cheek, C, Hays, R, Smith, J, Allen, P, Improving Case Study Research in Medical Education: a Systematised Review, *Medical*

Appendix: Table 1.

Date	Activity	Mother/patient	Medical professional/s	Family members
Mid 2016	Stage 3 breast cancer diagnosed, at age 88  3mth radiation therapy  Pneumonitis from radiation; steroid treatment		General Practitioner (GP) referral to General Surgeon  General Surgeon referral to Radiation Oncologist (RO) General Surgeon referral to Radiation Oncologist	
Jan/Feb 2019	Lower back pain that did not resolve in a few weeks		GP tested & diagnosed sciatica; referred to Neurosurgeon for cyst removal	
Early March	Malignancy detected in cyst		Neurosurgeon conducted further tests Referred back to RO	
Early March	Further tests, including daylong biopsy to ensure malignancy metastatic breast cancer	Experienced excruciating pain	RO referral to hospital staff	
15 March	Two-week radiation course begins		Radiologists	
17 March	Immobility; Unable to move from bed to toilet; mild shock and distress  Second treatment deferred for a day's recovery	Mum at home alone	RO	Walker hired Wrote to RO to advise; made explicit Mum's priority for highest quality end-of-life care, absence of aggressive intervention
19 March	Second treatment		Radiologist	
20 March	Extreme pain; immobile – wheelchair required  Session with RO  Fentanyl injections prescribed; admission to hospital for pain management & completion of radiation	Mum at home alone	RO	Daughter moved into mother's house to be closer to mother in hospital, & to visit daily
20 – 27 March	Radiation continued Steroid & anticonvulsant prescribed as pain & immobility increased, as diarrhea set in Oncology nurse indicated pain should have abated  Pall care consult ordered	In hospital Could only walk short distances with frame  Reaffirmed message that wanted end-of-life with as much independence and as little pain as possible	RO RO  Oncology Nurse  RO  Palliative Care (PC) Specialist	Daughter deferred to RO expertise
27 March to early April	Radiation completed; pain & immobility increased Second Pall Care consult with daughter Family meeting called by RO to suggest transfer to respite facility to wait on improvement in pain & mobility	Agreed to recommendation	RO, radiologist  PC specialist  RO	Daughter reaffirmed Mother's wishes  Daughters, son-in-law & grandson, RN
1-4 April	Discussion to determine real wishes  Public Pall Care Service	Didn't want to be a burden but real preference for privacy and comfort of own home	Referral from PC specialist	Mother & older daughter, with agreement of younger daughter; advised hospital & RO
4 April – 2 May	End-of-life care at home	Decline was marked by increased levels of pain, decreased mobility to the point of catheterization, inability to speak her needs, final days of unconsciousness when her heart expired from the matching increased levels of morphine	2 private PC Nurses 1 PC Nurse Practitioner	Older daughter oversaw, supported by younger & her husband

Appendix: Table 2.

<b>Tenets</b>	<b>GP</b>	<b>Neurosurgeon</b>	<b>Radiation oncologist</b>	<b>Palliative care specialist</b>	<b>Patient</b>	<b>Family</b>
<b>Personal mastery</b> <i>This requires each participant involved in decision-making to be clear about their personal goals for care, to strive to see clearly the objective reality of what is happening, and to be patient in thinking and discussing the above.</i>	Assume clinical oversight of care of the whole person.	Recognize terminal diagnosis; refer back to the GP.	Recognize terminal diagnosis; either refer back to GP, or initiate goals of care discussion before treatment	Be called upon early as participant	Be enabled to express goals for care	Be advocate for patient
<b>Mental models</b> <i>This requires participants to identify and articulate their own deeply held assumptions about care and how it is to be achieved.</i>	Continue active oversight/coordination. Do not fragment care through specialization	Refer back to GP. Do not fragment care through specialization.	Actively consult GP. patient and family about goals of care. Do not fragment care by focus on diseased part of patient	Advocate earlier inclusion by preceding clinicians	Challenge societal assumption of the need for specialist clinical treatment of disease	Challenge societal assumption of the need for specialist clinical treatment of disease
<b>Building shared vision</b> <i>This requires the development of a shared picture for the progression of care.</i>	Requires active coordination of patient's care	Requires view that the patient's care requires more than treating diseased part	Requires view that the patient's care requires more than treating diseased part	Impossible if 'last resort' option	Assumes early goals of care discussion	Assumes early goals of care discussion