King's Research Portal

Document Version
Publisher's PDF, also known as Version of record

[Link to publication record in King's Research Portal](#)

A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals

Sophie Pask[1], Cathryn Pinto[1], Katherine Bristowe[1], Liesbeth van Vliet[1], Caroline Nicholson[2], Catherine J Evans[1,3], Rob George[4], Katharine Bailey[1], Joanna M Davies[1], Ping Guo[1], Barbara A Daveson[1], Irene J Higginson[1] [iD] and Fliss EM Murtagh[1,5]

Abstract

Background: Palliative care patients are often described as complex but evidence on complexity is limited. We need to understand complexity, including at individual patient-level, to define specialist palliative care, characterise palliative care populations and meaningfully compare interventions/outcomes.

Aim: To explore palliative care stakeholders' views on what makes a patient more or less complex and insights on capturing complexity at patient-level.

Design: In-depth qualitative interviews, analysed using Framework analysis.

Participants/setting: Semi-structured interviews across six UK centres with patients, family, professionals, managers and senior leads, purposively sampled by experience, background, location and setting (hospital, hospice and community).

Results: 65 participants provided an understanding of complexity, which extended far beyond the commonly used physical, psychological, social and spiritual domains. Complexity included how patients interact with family/professionals, how services' respond to needs and societal perspectives on care. 'Pre-existing', 'cumulative' and 'invisible' complexity are further important dimensions to delivering effective palliative and end-of-life care. The dynamic nature of illness and needs over time was also profoundly influential. Adapting Bronfenbrenner's Ecological Systems Theory, we categorised findings into the microsystem (person, needs and characteristics), chronosystem (dynamic influences of time), mesosystem (interactions with family/health professionals), exosystem (palliative care services/systems) and macrosystem (societal influences). Stakeholders found it acceptable to capture complexity at the patient-level, with perceived benefits for improving palliative care resource allocation.

Conclusion: Our conceptual framework encompasses additional elements beyond physical, psychological, social and spiritual domains and advances systematic understanding of complexity within the context of palliative care. This framework helps capture patient-level complexity and target resource provision in specialist palliative care.

Keywords

Complexity, palliative care, human development, classification, qualitative research

---

What is already known about the topic?

- Palliative care patients are often characterised as complex but no standardised definition or conceptual framework for complexity exists in palliative care.

---

[1]Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, London, UK
[2]Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London, London, UK
[3]Sussex Community NHS Foundation Trust, Brighton, UK
[4]St Christopher's Hospice, London, UK
[5]Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK

Corresponding author:
Sophie Pask, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, Bessemer Road, London SE5 9PJ, UK.
Email: sophie.pask@kcl.ac.uk

- Healthcare systems are using casemix classifications increasingly to allocate resources and ensure maximum value and efficiency.
- Casemix classifications require the complexity of patients' needs to be captured at an individual patient-level, but this is poorly standardised in specialist palliative care.

What this paper adds?

- This article presents a conceptual framework to understand complexity in specialist palliative care, developed from patient, family and professional perspectives.
- Bronfenbrenner's Ecological Systems Theory has been adapted to provide a novel framework for understanding complexity in specialist palliative care.
- Number, severity, range and temporality of needs should be considered in the development of a meaningful casemix classification for specialist palliative care, along with additional aspects such as 'pre-existing', 'cumulative' and 'invisible' complexity.

Implications for practice, theory or policy

- This framework identifies and conceptualises the sources of complexity in palliative care and provides a comprehensive understanding of complexity for palliative care providers.
- This has implications for how services themselves recognise and respond to needs; improving understanding of complexity will support more integrated and targeted care.
- A casemix classification for specialist palliative care in the United Kingdom could reflect patient-level complexity as described by this framework and be feasible in practice.

Background

Populations are ageing and more people are living with chronic conditions and comorbidities.[1–4] People with advanced progressive illness have a range of complex needs and symptoms,[5–7] and their care is increasingly multifaceted. Specialist palliative care resources should be targeted to those with the most complex needs.[8–12] However, current evidence demonstrates that access to palliative care is determined not by level of complexity of need but more often by diagnosis, physical symptoms, age, ethnicity, socioeconomic factors and geography.[2,8,13–15] Referral may also be delayed because of the absence of standard definitions of what constitutes a palliative care patient or reasons for referral are not widely accepted.[8,14–17]

Palliative care patients seen are generally characterised as complex, with multiple symptoms, psychological, existential and social concerns,[6,18–21] but no standardised definition of complexity exists and research is limited. In palliative care, complexity is commonly characterised as the number, severity and interaction of domains in the Holistic Common Assessment, a widely used framework for comprehensive palliative care assessment.[22] Studies considering complexity have largely been in decision-making, multiple chronic conditions, paediatric care or general healthcare and have described complexity more broadly (beyond the individual).[23–31] Fernández-López et al.[20] defined four levels of complexity for people nearing end-of-life (no complexity, low, medium and high), which establish intervention criteria for resource allocation, but without further validation. A recent study has

also explored a predictive model of complexity (also adopting tiered levels) in palliative care, but only explores intervention and patient-level complexity in advanced cancer patients.[32]

Understanding complexity matters for several reasons. First, improved understanding of complexity in the last year of life is needed for more effective and integrated care, to ensure the different elements of care are brought together to manage patient needs[12,33] Second, understanding and ranking levels of complexity would help distinguish between generalist and specialist palliative care.[8,17] Third, in healthcare, there is increasing use of casemix classifications. These are classifications based on patient-level criteria, which allow the grouping of patients in terms of the resources needed to meet their needs.[34] Casemix criteria can effectively characterise which cases are more or less complex.[35] Such casemix classifications were pioneered in the United States with 'diagnosis related groups' (DRGs)[36,37] and have been used in many countries since to develop prospective payment systems, mainly for hospital financing.[38,39] Healthcare Resource Groups (HRGs) underpin the main casemix classification adopted in England.[34] HRGs are patient classes derived from information about diagnosis and procedures, aiming to deliver fair and equitable reimbursement for healthcare services.[34]

Although casemix classifications have been widely used to manage resources across healthcare, they have rarely been applied to palliative care. Other classifications have been used to group and analyse cost, but have only

been applied to breast cancer.[35] Existing classifications (such as DRGs and HRGs) are based on diagnoses and procedures, but for patients receiving palliative care, the goal is to enhance quality of life and maintain or maximise current health and functional status, in the context of advanced incurable illness.[40] Hence, we need different classifications for palliative care.[41–43] Only in Australia has such a casemix classification for palliative care been developed.[43] Criteria such as diagnosis and procedure were found to be ineffective in classifying whether those with palliative care needs were either more or less complex.[41] Instead, 'phase of illness' and 'problem severity' were found to be the better indicators of complexity and corresponding resource use.[41,44] However, it is not clear whether these patient-level criteria are applicable internationally, acceptable to stakeholders and best reflect complexity in palliative care.

The aim of this study is, therefore, to explore what makes a palliative care patient more or less complex, to develop a conceptual understanding of complexity and to consider how complexity might best be captured at patient-level in specialist palliative care.

Method

Study design

Qualitative study using in-depth interviews, reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) guidelines.[45]

Participants and setting

Participants were sampled purposively, to achieve maximum variation, by personal and/or professional background, geographical location and experiences of settings of care (hospital, hospice and community).[46] Purposive criteria were selected from existing evidence by the research team, the Programme Steering Committee and the Patient and Public Involvement (PPI) advisory group. Participants from the eight participating sites were approached and subsequently interviewed if willing to participate. The sample comprised patients and family carers, healthcare professionals (i.e. doctors, nurses and allied professionals), managers and senior leads (including national leads) in palliative care. Recruitment took place between October 2014 and June 2015 in six UK centres (North London, South London, Sussex, Cambridge, Dorset and Yorkshire).

Data collection

Face-to-face, semi-structured interviews were conducted by four researchers (C.P., K.Ba, L.V. and S.P.) in the participant's preferred setting. A topic guide was developed from a review of evidence on complexity, potential criteria for casemix, existing casemix classifications in palliative care and predictors of resource use in the last year of life. It was refined by our PPI advisory group, the research team and the Programme Steering Committee (See Online Appendix 1). Written informed consent was obtained prior to interview.

The interview began with a discussion of complexity in palliative care and how it could be characterised. Two vignettes, giving examples of low and high complexity, were then used to help focus on concrete examples and elicit further discussion. These were developed with our PPI advisory group (see Online Appendix 2). Interviews then explored how complexity might be measured at an individual patient-level.

To increase the credibility of the data, interviewers summarised the interview back at the end to allow the participant to verify and clarify any misconceptions or add additional information. Data collection continued until data saturation was reached. All interviews were digitally audio recorded, anonymised and transcribed verbatim to ensure confidentiality. A distress protocol was developed and implemented to minimise risk of potential harm to participants.

Analysis

Interviews were analysed (by C.P. and S.P.) using the five analytical steps of Framework analysis: (1) familiarisation, (2) identifying a thematic framework, (3) indexing, (4) charting and (5) mapping and interpretation.[47–49] Framework was considered the optimal approach to allow both an inductive and deductive approach, to facilitate comparison across stakeholder groups and to support the service delivery and policy focus of this research.[47,48,50] Emerging themes were discussed between three researchers (C.P., K.B. and S.P.) to improve the confirmability and dependability of the findings. Charts were created for each theme, grouped by stakeholder type, and used to explore stakeholder assonance and dissonance among perspectives on each theme and subtheme. The COREQ guidelines were used throughout the study design, data collection and analysis process to enhance trustworthiness and methodological rigour.[45] Analysis was managed using NVivo software (Version 10).

Ethical approval

Approved by the King's College London Research Ethics Committee (BDM/14/15-2).

Results

65 participants (of 69 approached) were recruited (94%); four people declined or were unable participate. Interviews ranged from 28 to 118 min with a median of 52 min. Participant characteristics are outlined in Table 1.

Table 1. Participant characteristics.

Participant characteristics (n = 65)	Patient and family carers (n = 10)	Health professionals (n = 38)	Managers and senior leads (n = 17)
Age (years)			
<40	0	5	2
40–49	0	16	8
50–59	2	13	7
60+	8	4	0
Gender			
Male	3	13	3
Female	7	25	14
Ethnicity			
White British	6	33	12
Other	4	5	5
Geographical location			
North London	1	3	5
South London	6	13	1
Sussex	0	7	1
Cambridgeshire	0	1	0
Dorset	0	4	1
Yorkshire	3	10	1
National	0	0	8
Professional background			
Senior Doctor	–	11	
Junior Doctor	–	3	
Senior Nurse	–	11	
Junior Nurse	–	6	
Senior Pharmacist	–	1	
Manager	–		9
Senior Lead	–		8
Social Work and Welfare	–	3	
Spiritual Care Provider	–	3	

We found that participants identified components of complexity relating to (1) the person; (2) changing and dynamic aspects of illness and needs; (3) the person's interactions with family, health professionals and immediate settings; (4) palliative care services/systems; and (5) societal influences. We explored a range of existing theories in psychology, education and sociology, which were relevant to these emergent findings.[51–53] We recognised strong parallels between our emergent findings and the dimensions proposed by Bronfenbrenner's Ecological Systems Theory[54] (i.e. the world of the child as influenced by their social network and interactions, services and systems, and society, as well as changes over time because of dynamic interactions within and between these proposed 'levels'). Therefore, we adapted Bronfenbrenner's theory to underpin our data mapping and interpretation (see Figure 1). Findings are presented utilising the five systems of Bronfenbrenner's theory: microsystem (the individual and their social network), chronosystem (changes over time), mesosystem (interactions between the individual and their social network), exosystem (systems and services) and macrosystem (societal attitudes and culture)[54] and how these apply to palliative care.

The microsystem: the person's needs and characteristics

The microsystem consists of the person's needs and characteristics, which directly influence whether they are more or less complex.

The person's needs

Participants – patients, family members and professionals – discussed complexity in terms of physical, psychological, social and spiritual domains. Participants emphasised communication and social needs as important in determining complexity, these included information needs, social responsibilities (e.g. caring for children) and communication (e.g. English not a first language or understanding of medical information):

> … we have a lot of people who don't speak English as their first language so we have to use interpreters or we have to use

other family members. That adds to the complexity. (1058, Social Worker)

I think it can work in both, in terms of education around their illness, you can sometimes have people who look into things in so much depth and actually have read everything on the internet, and come to you with all the, 'And I would like a third opinion from somebody in [country name]', and so that in itself is complex because you have to manage that with the health resources that you have. (1028, Senior Clinician)

The person's characteristics

A few participants discussed how demographic and clinical characteristics – such as age and diagnosis – influenced complexity. For instance, acceptance of advancing illness and deterioration was influenced by age, and in this way, could reduce complexity:

I think the age of the patient is a big factor too because I do feel that when someone's coming towards the end of their life, it's easier to accept what's happening in general … (1015, Senior Clinician)

Some participants drew on personal characteristics beyond needs and highlighted how these affected a person's understanding of their illness, decision-making, navigation of the healthcare system and experiences of care. These included the following: health literacy; confidence; coping and resilience; mental capacity; cultural context; and preferences and priorities. They emphasised the impact of illness on these characteristics and how these aspects influenced presentation, and hence complexity:

People are afraid to complain very often in a hospital setting (…) It's very easy to be bullied by somebody when you're immobile and you're emotionally fragile … (1031, Family Carer)

Pre-existing complexity

Some participants discussed how a patient's life can have qualities of complexity before they receive palliative care, such as long-standing difficulties with finances and/or housing, dependents, bereavements, mental health needs, homelessness, substance misuse, relationships and lifestyle. For example, the demands of being a single mother adds to complexity of life:

… she has to look after her kids, so she hasn't got her husband with her any longer. So, forget about the complexity of her illness, the complexity of just normal life is much higher (1004, Patient)

Cumulative complexity

Most felt that both the number of problems a person experiences and whether problems were experienced across several or all domains strongly influenced complexity and were 'cumulative'. The likelihood of each problem

exacerbating other domains was recognised, as in the concept of 'total pain' described by Cicely Saunders.[55,56]

Participants were also cautious about considering things in isolation, yet provided examples where single aspects, such as severe pain or having dependents, affected all areas cumulatively and could impact on a patient's entire experience. A few participants illustrated how one severe problem could sometimes lead to highly complex needs:

… the reality is that somebody who has multiple issues or multiple problems may not present as complex as someone who has one problem, which may cause the multi-professional team a lot more thought and work … (1054, Spiritual Lead)

The chronosystem: changing complexity over time

The chronosystem refers to changes in a patient's needs, circumstances and environment over time. In palliative care, this often reflects the prevailing uncertainty related to disease trajectory and care. However, other aspects of time were also seen to influence complexity, such as long-term caregiving burden, late referral in non-cancer or shorter disease trajectory.

Most participants emphasised how quickly changes can occur. They described patients' needs as fluctuating, dynamic and sometimes rapidly changing. There are related issues of uncertainty when changes occur and how to manage problems that suddenly arise:

… a patient could be high complex and then you sort lots of things out, you get symptoms under control, you put equipment in, you put some support in, and so it changes. And then something else happens, so it's that undulation, it's that toing and froing, that in and out of complexity (...) patients don't stay the same for very long periods of time, and there's ebbs and flows. (1012, Senior Clinician)

Participants – especially professionals in palliative care – spoke of how immediate needs influence complexity and require timeliness of care, prioritisation and rapid caseload decisions:

Yes, some things may be because of the speed that [name] is dying, do need to be sorted out. If she has got no other support then social care will really need to come in and give her the options of what is going to happen with her children. It is very difficult. (1034, Manager/Senior Lead)

Participants in all groups felt that complexity was not usefully captured as a snapshot and needed regular review to ensure that services are responsive and flexible to needs as they change:

… within palliative and end-of-life care, means things change so rapidly, so you need a really responsive service, and if you haven't got that then you can't match the service to the person's needs. (1014, Senior Clinician)

Some participants also highlighted duration of needs as important in caregiver burden and its effect on complexity:

> … duration has a part to play because people need stamina to manage really long-term conditions. And it's not only the patient themselves; their families and their carers need to be able to deliver sustained input and I think that's really hard when it's over prolonged periods. (1017, Manager/Senior Lead)

The mesosystem: the interactions between the person, their family and health professionals

The mesosystem represents the interactions that occur between the person, the main people (e.g. family or healthcare professionals) and settings of care (e.g. hospice, hospital and community). Complexity here was largely expressed in terms of the interactions between the patient and their healthcare providers, and between the patient and their family as well as friends, spiritual networks and other support groups. Complexity can be reduced by strong supportive links or exacerbated by limited support.

Dissonance between patients, families and health professionals

Participants spoke of dissonance between patients, families and health professionals as pertinent. Some highlighted the difficulties that could arise from differences in how patients and professionals would prefer to manage their care:

> … you may have a couple of things wrong with you, and as a patient you may prefer one thing to be done. Meanwhile, as a professional you may actually think the other thing needs to be done first [laughs]. So, I mean, it will bring possible conflict. (1004, Patient)

> So, I think what's the patient's agenda and how they want to handle life is much less tidy than the healthcare professionals would like it to be. And there's a great danger that we tell people how they should handle their final period of life. (1023, Senior Clinician)

Similarly, participants reported challenges when patient's and professional's beliefs differ and how this could affect experience of care. For instance, dissonance in spiritual perspectives may lead to misinterpretation of emotional well-being:

> When the family then says, 'Right, I don't want you to tell him', or, 'I don't want you to give him the morphine', as a profession we're thinking you're not the patient, I need to listen to the patient, thank you very much. Then you alienate the family and the family says I don't want you coming in then because if you're going to come in here and upset my

loved one, I don't want you here. To me, as a professional, a big part of our job is understanding people's culture (…) Then I need to walk with the family, understand what is important and then manage the symptoms in accordance with that. That, to me, is complex. (1049, Manager/Senior Lead)

Others referred to the way dissonance between patients and family wishes, increased complexity:

> You can have families who are warring or arguing, different perspectives on what should happen to their loved one and that can pull everybody in different directions. (1034, Manager/Senior Lead)

Engagement, prejudice and 'invisible' complexity

Health professionals drew attention to examples where patients may choose not to engage with services and how this can increase complexity. This includes patients declining opportunities to talk about care at the end-of-life and some groups (e.g. substance or alcohol misusers) that struggle at times to interact with healthcare services:

> I suppose drug and alcoholic abuse, in terms of a specific group of people, just because, again, these patients don't tend to engage as well. They tend to have more erratic lifestyles. Therefore, asking them to come in or be in at a certain time to go and visit them is harder. (1057, Junior Clinician)

Perceptions and prejudice were also thought to influence care and complexity. Participants described how some diseases are stigmatised, which triggers a different set of social responses from family and professionals, and impede a patient's freedom to disclose information:

> I do think there are some diseases that make it more socially complex, or potentially more socially complex. So (…) liver cancer being associated with hepatitis B, which was more associated with intravenous drug users, triggers a different reaction in their social set. You know, in the family, in the friends, in the professionals sometimes even, which makes the whole situation more complex to manage. (1019, Manager/Senior Lead)

Several participants highlighted the issue of 'invisible' or hidden complexity when people do not engage with healthcare services, for example, those with long-standing depression or older people who may not seek help so readily:

> I've just left a gentleman on the ward. He is very depressed (…) He's not taking up anybody's time because he's feeling very helpless and hopeless. So, the complexity is there but he's not engaging with any of it (…) Actually, a nurse on the ward could think he's really easy to look after but actually his needs are really complex. (1013, Senior Clinician)

> I think there is an impact with age on the traditions of how they interact with services – so you do find people in all

spheres who are a bit more elderly but who wouldn't dream of contacting somebody in the middle of the night. So, how they interact with their health services might be more traditional and lead to them avoiding that (1028, Senior Clinician)

The exosystem: service- and system-level factors

The exosystem comprises services and systems that the person is not directly part of, yet, which influence the care they receive. This refers, for instance, to how multidisciplinary teams work/are structured (including provision or absence of staff training), how services coordinate care (e.g. electronic palliative care coordinating systems/electronic records) and local service governance and commissioning.

Multidisciplinary team meetings and coordination of care

Participants – especially professionals – emphasised how effective multidisciplinary team meetings can lessen complexity by responding efficiently and well to complex needs; multidisciplinary teams may be essential for more complex patients:

> The whole purpose of having a multidisciplinary approach to palliative care is to handle complexity (…) No one profession has all the skills that dying people and their families need. (1016, Senior Clinician)

However, many highlighted concerns that ineffective multiprofessional involvement could increase complexity through problems with planning and disjointed care:

> … she's got breast cancer with the chemo, the pain and the depression, if they're all being managed by one team that's fine, but if she's seeing different teams it could be very disjointed. (1002, Patient and Family Carer)

The majority saw good communication within and between teams/services as key to delivering effective patient and family care and managing complexity well.

Service availability and capacity

Most participants felt resource constraints may be a factor in complexity as needs are not effectively addressed:

> … someone's quite complex and actually would benefit from a social worker and regular nurse visits to their home or being admitted for respite care or whatever. But actually, if you don't have the resources for them to access that then it doesn't matter that they're more complex, but you're still not going to meet the need that you've identified because you're constrained by the resources available. (1020, Manager/Senior Lead)

Some participants spoke of how care may become more complex if staff lack the necessary skills or experience, as they may not have the expertise to address and respond to needs, thereby increasing apparent patient complexity.

> … complexity [sometimes] arises because the professional makes it complex, because of their perception of the issue or perception of it as a problem (…) So for some people advance care planning could be seen as a complex issue, for others it wouldn't be. (1048, Manager/Senior Lead)

Participants from all groups discussed the importance of training as a service factor influencing complexity. In particular, professionals highlighted that specific training is required for certain groups (e.g. homeless people, those with learning disabilities or dementia):

> So those with say learning disability or homeless people who might have needs and that access a service. (…) And there, with that, there may be greater complexity from lack of experience in seeing these patients that there may be additional factors that aren't immediately apparent. (1005, Senior Clinician)

The macrosystem: population and society

The macrosystem refers to the wider societal and cultural context, within which the other systems are embedded. Although most 'distant' from the person, the findings suggest this has profound influence over complexity. Within palliative care, the macrosystem includes: the system-wide structure of palliative care (e.g. services, funding and resources), the structure and organisation of health and social care systems, end-of-life care policies and values in society (e.g. cultural values, stigmas and beliefs).

Wealth and deprivation can also influence complexity with deprived areas receiving limited resources and being more 'neglected' (e.g. less access to hospices):

> I think areas of poverty, areas of wealth have a huge impact. I think the multiplicity of all the different providers in the area has another impact. Some things you're able to get in some areas, some things you're not able to access in other areas, so there's lots of inequity in that sense. (1038, Senior Clinician)

Some participants discussed professional and societal cultures' failure to recognise deteriorating health and dying, and its impact on complexity:

> There is a whole issue about failure of the health service or social care to recognise either that somebody is dying or to provide services. There might be good and easy solutions to reduce complexity but if they are not available or people don't know how to access them then that increases complexity. (1034, Manager/Senior Lead)
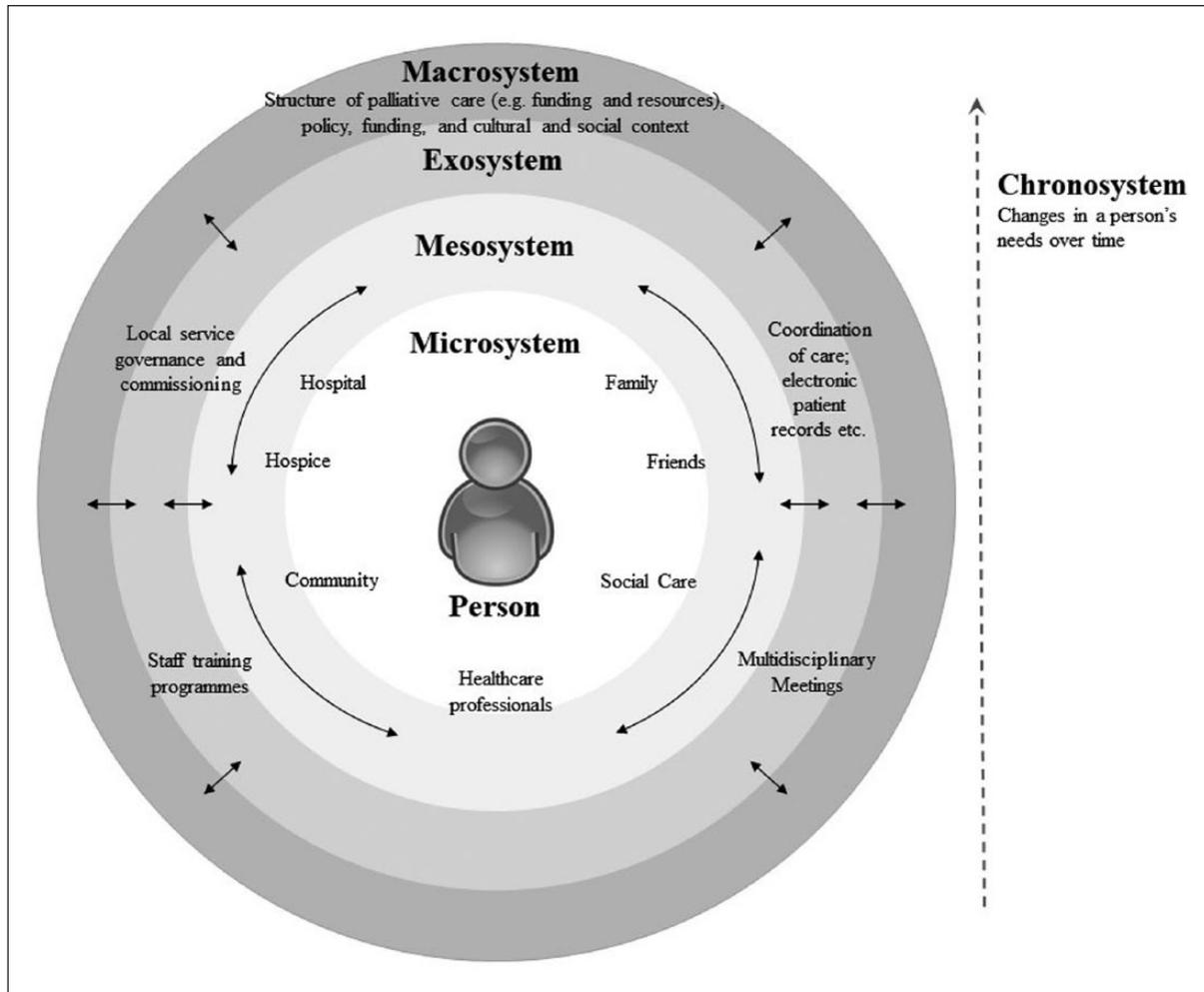
Figure 1. A framework of complexity in the palliative care context.

Capturing complexity at individual patient-level

Interview findings illustrated diverse views on capturing complexity using individual patient-level criteria (see Online Appendix 3). The main themes have been summarised below. For more details regarding the coding frame, see Online Appendix 3.

Acceptability of capturing and classifying complexity

In general, participants stated that assessing complexity at individual patient-level was important. Some stated that having a quantifiable measure of complexity was crucial to ensure appropriate services and the fairest possible resource allocation. Participants had mixed views about whether it was acceptable to classify people's individual needs into specific groups from high to low complexity. Most felt this was acceptable, but a few had concerns about possible negative associations of using broad

categories that may detract from the uniqueness of the individual:

> I think, in some ways, it has to be possible, really, because I think otherwise it's very hard to allocate resources and allocate yourself and your time, really. Yes, I do think it's possible and I do think it's very difficult, and I think there are lots of different variables to take into account. (1038, Senior Clinician)

Ways to capture complexity at individual patient-level

Participants suggested various ways to measure or capture complexity: some focused on the key components to be included, others suggested techniques to compute or stratify complexity. The four palliative care domains (physical, psychological, social and spiritual) were seen as the core components, and both patient/family participants and professionals reported needs as additive or cumulative. Participants suggested various means of scoring or

classifying complexity. Proposed techniques included composite scores, hierarchies, graphs, algorithms or mathematical models. However, some participants suggested it may be too complicated to try and reflect complexity beyond a fairly simple classification; and that referrals might be helpful to elucidate complexity:

> … somehow you have to try and then relate each one, the economic to the physical, and then to the emotional (…) so therefore you've got the complexity of the illness, complexity of the finance, complexity of the social and it's trying to work out some sort of matrix which will then, say the overall complexity score for this person is … (1004, Patient)

> … you're one point for every person that you're referring them onto. So, if you refer them onto an OT, that's one point, if you refer them to the Social Worker, that's another one (…) if you're having to get the GP to go and see them pretty soon afterwards … (1007, Senior Clinician)

Some healthcare professionals shared views that certain elements may be missed when capturing complexity at an individual patient-level (e.g. dependence and mental health). Existing resilience and support networks were also seen as major influences on how complexity manifested in any one individual and how hard it is to capture systematically:

> We've got a couple of [patients], they ring up virtually every day for advice. That is time-consuming, but, once again, are we missing something? Is it their mental health that is the issue and we're just addressing the physical symptoms? Have they no support mechanisms and there are no carers, and we're being phoned because we're there? I wouldn't class those as complex. (1062, Senior Clinician)

Potential benefits of classifying complexity

The benefits of measuring and classifying complexity at individual patient-level were described most often by the managers and senior leads, and least frequently by the patient and carer stakeholder group. A standardised way to classify complexity was recognised by most professional participants as providing a 'common language' and shared understanding to improve communication across different service providers. Some participants discussed how classifying complexity might help determine when specialist or generalist palliative care input was needed:

> I think it's essential that you have a sort of a consistent standardised framework for measuring complexity (…) so it gives you that common language (…) to compare different patient cohorts and casemix across different populations, across different providers and to facilitate communication between providers and commissioners and the like. (1025, Manager/Senior lead)

More participants – including patient participants – viewed a classification of an individual's complexity as an efficient and fair way to tailor resource provision. In contrast, a few participants, from the patient and caregiver stakeholder group, believed that all patients and families should be offered the same palliative care resources regardless of their level of complexity:

> … we just say, 'Everybody gets all of this. Everybody'. So, we almost pour a bucket of water over everyone, so everybody gets wet. What we want to do is to have a bucket of water which has a spout on it, so we can pour the water on the ones who need it at the time. (1054, Spiritual Lead)

> I think Arthur has – we're – on the surface we're saying his complexity is a lower level, but actually the – this – everything that is offered to him – he needs to have the same offering but he maybe doesn't take advantage of it. (1002, Patient and Family Carer)

Potential challenges of classifying complexity

Some participants described challenges that need to be overcome for this approach to be meaningful and workable for specialist palliative care. Complexity groupings should be responsive and reflect the changing needs of palliative care patients. Some were concerned that if the complexity groupings were not sensitive to these changing needs, then the patient would not be able to access the necessary resources should their status change:

> … one just has to make sure that each case is reviewed and there is not too much officialdom (…) I think, that make sure that people are not just given one category and even when it's changed, you know, nobody is listening … (1003, Family Carer)

Participants reported that some elements of patient complexity may not be easily captured by objective measurements; exploration of issues in a personal clinical encounter will always be needed. Participants also had concerns about the logistics and resource intensiveness of data collection about patient complexity – how often would data need to be collected, are the measures appropriate, is the right infrastructure in place (e.g. information technology) and does it run alongside clinical data collection? Staff training was also felt to be important:

> I don't know quite how detailed that's going to be and how everyone's got the resources to keep on measuring, monitoring and reporting back on that kind of thing, so I quite don't know how that would [work] … (1015, Senior Clinician)

Discussion

This study provides a comprehensive conceptual framework of complexity based on empirical evidence derived from patients, family carers and professionals. It adapts Bronfenbrenner's Ecological Systems Theory.[54] His original theory explained how a child – at the centre of the

framework – developed in response to their context and environment. We apply this theory to palliative care, adapting the framework to be patient-centred, and explain how a patient interacts with their context and environment when living with an advanced illness. While palliative care has long recognised physical, psychological, social and spiritual holistic domains, we found complexity to go far beyond these four domains. This research reveals that we need to consider pre-existing and cumulative complexity, the dynamic aspects of complexity, invisible complexity, service-/system-level factors and societal influences to consider and meet patients' needs comprehensively and effectively.

Characterising complexity in terms of Bronfenbrenner's microsystem, mesosystem, exosystem, macrosystem and chronosystem levels is supported by existing literature in multimorbidity, chronic conditions and general healthcare,[26,27,30] which demonstrate that complexity goes beyond the individual, includes contextual drivers, and derives from multiple sources (e.g. system-level and service-level aspects).[9,26,30,57] This article provides a more comprehensive understanding of complexity as applied to palliative care. The findings have resonance with the cumulative complexity model of Shippee et al.,[27] which emphasises the progressive and cumulative nature of complexity, and how this shapes access to and experiences of healthcare. Prior evidence also indicates relationships between components of complexity as neither final nor static.[26,27,30] Our framework presented here emphasises the dynamic interactions in palliative care. In addition, the concept of cumulative complexity presented in this model has particular significance for palliative care – comparable to the concept of 'total pain'.[55,56] This addresses the need to palliate the person as a whole, considering relationships between components and systems.

We have drawn on a range of stakeholders' perspectives (including patient and family carers) to identify characteristics of complexity which are not usually reported. The Holistic Common Assessment,[22] commonly used in assessing patient needs in palliative care, includes some of these aspects (cultural context, mental capacity, preferences and priorities). Our interviews uncovered additional aspects that could be included in this assessment, such as health literacy,[58] coping and resilience[59] and empowerment.[60,61] These aspects have been described independently in other research studies. This framework also emphasises how dissonance between patient, family and/or professionals, as well as the level of engagement with healthcare, may strongly influence complexity. Such dissonance substantially increases the amount of time professionals need to spend to deliver care effectively. Invisible complexity – unrecognised by healthcare providers – is new and requires further study. As Safford et al.[26] highlight, congruence between patients, professionals and healthcare systems emerged as crucial for effective and patient-centred care. It is well-established

that patients' and healthcare professionals' perspectives on symptoms[62] and quality of life[63] do not always overlap; other areas of dissonance – such as contradictory or unexpected preferences – also influence complexity.

Limitations

Our sample consisted mainly of senior clinicians and participants largely from London, this imbalance may influence the transferability of findings. However, this study expanded on previous literature[20] by incorporating experiences from patients and family carers in addition to professionals from multiple disciplines to form unique data examining complexity in palliative care. We made conscious efforts to ensure that the data presented were representative of the views from all stakeholder groups. We recognise that there were a limited number of patients and family carers involved as participants, compared to other stakeholder groups. There were certain challenges in accessing these particular participant groups through participating sites, as well as considerations specific to patients living with advanced illness and their carers (e.g. fatigue and caring commitments) outlined by previous research.[64] Findings were, therefore, presented and discussed with the PPI advisory group to aid interpretation. The framework would need to be explored further with this population.

As the main focus of this article was to present a framework of complexity, the authors were only able to highlight and briefly describe where assonance and dissonance were present between stakeholder groups.

Due to staff change over in the project and volume of interviews collected, four researchers conducted the interviews. Some joint interviews were conducted to ensure that interviewing styles were similar and were assisted by the topic guide. Researchers would also meet to discuss the interview progress and emergent themes.

Applying the framework in practice

Our framework provides a structured and comprehensive way of considering complexity in palliative care. This understanding of complexity will allow us to prioritise and target care better and helps move towards more effective and integrated care.[12,33] Participants highlighted the importance of having a shared understanding of complexity across different specialist palliative care providers and settings. There is still confusion among generalists regarding the timing of integrating specialist palliative care.[65] Frameworks that accurately capture patient-level complexity allow us to communicate the specialist role more clearly and target limited resources more effectively to meet patients' needs.

This study also indicates that complexity can be captured at the individual patient-level. A casemix

classification needs to measure holistic needs (physical, psychological, social and spiritual) of patients and families, but we also demonstrate that other aspects of complexity are also important, such as information about patients' personal characteristics, resources (e.g. coping/resilience, vulnerability and dependence), their existing support networks and the transparency (or otherwise) of their degree of complexity. This is important practice: the Australian casemix classification, for instance, takes this into account by including data on the number and severity of problems alongside 'Phase of Illness'[66] and functional status.[41,67]

Our proposed framework also incorporates factors in the macrosystem that have not been identified in other models of complexity.[20,26,27,30] This provides insights to address current challenges, such as who accesses palliative care, how people access palliative care and the best way to use limited resources.[8–10,13,33] Our framework and considerations of how to measure complexity at an individual-level together give us the means to consider and address complexity systematically to advance both theory and practice in palliative care.

In particular, services should seek out 'invisible complexity', the patient who cannot advocate for themselves and may be overlooked in highly-pressured health and social care services. Clinical and senior leads, chief executives and commissioners also need to consider the quality of interactions between professionals and patients/families, how responsive and flexible their services are and the extent to which 'the system' increases complexity by inflexibility or inability to respond to rapidly changing needs.

Future research

Future research needs to assess how complexity can be measured and reported in a standardised way. We also need to explore further how this understanding of complexity can be applied practically and how it might apply to individual patients in particular. Further research is also needed to develop our understanding of aspects of complexity within the exosystem (services/systems) and macrosystem (societal influences), and to explore further the notion of 'cumulative' and 'invisible' complexity within palliative care.

Conclusion

This conceptual framework reflects the reality of patients' and families' lives as they face advanced illness, as perceived by patients, families and professionals in palliative care. It emphasises that considering physical, psychological, social and spiritual domains is not enough to characterise complexity. 'Pre-existing', 'cumulative' and 'invisible' complexity are also important, as is the way professionals and services interact with people and their families. Services need to be flexible in how they respond to individuals and to adapt to dynamic and changing levels of complexity, if they are to meet needs effectively.

It is acceptable to measure complexity at the individual patient-level, but this needs to incorporate key components of complexity. Any implementation of a casemix classification in palliative care will need to be tempered with the feasibility of collecting complexity data in clinical practice.

ORCID iD

Irene J Higginson https://orcid.org/0000-0003-1426-4923

References

1. Marie Curie Cancer Care. *Triggers for palliative care*. London: Marie Curie Cancer Care, 2015.
2. Dixon J, King D, Matosevic T, et al. *Equity in the provision of palliative care in the UK: review of evidence*. London: Personal Social Services Research Unit, London School of Economics and Political Science, 2015.
3. Effiong A and Effiong AI. Palliative care for the management of chronic illness: a systematic review study protocol. *BMJ Open* 2012; 2: e000899.
4. O'Brien T. The impact of an aging population on palliative care. *J Pain Palliat Care Pharmacother* 2013; 27: 389–391.
5. Cancer Action Team. *Holistic common assessment of supportive and palliative care needs for adults with cancer: assessment guidance*. London: Cancer Action Team, 2007.

6. Fitch MI. Needs of patients living with advanced disease. *Can Oncol Nurs J* 2005; 15: 230–242.

7. Langton JM, Reeve R, Srasuebkul P, et al. Health service use and costs in the last 6 months of life in elderly decedents with a history of cancer: a comprehensive analysis from a health payer perspective. *Br J Cancer* 2016; 114: 1293–1302.

8. Grande G. Access to palliative care. In: Cohen J and Deliens L (eds) *A public health perspective on end of life care*. Oxford: Oxford University Press, 2012, pp. 86–97.

9. Luckett T, Phillips J, Agar M, et al. Elements of effective palliative care models: a rapid review. *BMC Health Serv Res* 2014; 14: 136.

10. Walshe C, Todd C, Caress A, et al. Patterns of access to community palliative care services: a literature review. *J Pain Symptom Manage* 2009; 37: 884–912.

11. Wasson K and George R. Specialist palliative care for non-cancer patients: the ethical arguments. In: Addington-Hall J and Higginson IJ (eds) *Palliative care for non-cancer patients*. Oxford: Oxford University Press, 2001, pp. 239–250.

12. Care Quality Commission (CQC). A different ending: end of life care review, http://www.healthwatchharingey.org.uk/news/different-ending-end-life-care-review-cqc (2016, accessed 21 May 2016).

13. Hughes-Hallett T, Craft A, Davies C, et al. *Palliative care funding review: funding the right care and support for everyone*. London: United Kingdom Palliative Care Funding Review Team, 2011.

14. Bestall JC, Ahmed N, Ahmedzai SH, et al. Access and referral to specialist palliative care: patients' and professionals' experiences. *Int J Palliat Nurs* 2004; 10: 381–389.

15. Mitchell H, Noble S, Finlay I, et al. Defining the palliative care patient: its challenges and implications for service delivery. *BMJ Support Palliat Care* 2015; 5: 46–52.

16. Murray SA and McLoughlin P. Illness trajectories and palliative care: implications for holistic service provision for all in the last year of life. In: Sallnow L, Kumar S and Kellehear A (eds) *International perspectives in public health and palliative care*. Oxford: Routledge, 2012, pp. 30–51.

17. Farquhar M, Grande G, Todd C, et al. Defining patients as palliative: hospital doctors' versus general practitioners' perceptions. *Palliat Med* 2002; 16: 247–250.

18. Arnold BL. Mapping hospice patients' perception and verbal communication of end-of-life needs: an exploratory mixed methods inquiry. *BMC Palliat Care* 2011; 10: 1.

19. Higginson IJ, Hart S, Koffman J, et al. Needs assessments in palliative care: an appraisal of definitions and approaches used. *J Pain Symptom Manage* 2007; 33: 500–505.

20. Fernández-López A, Sanz-Amores R, Cía-Ramos R, et al. Criteria and complexity levels in palliative care. *Med Paliativa* 2008; 15: 287–292.

21. Higginson IJ and Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *Cancer J* 2010; 16: 423–435.

22. National Cancer Action Team and NHS Improving Quality. Holistic common assessment of supportive and palliative care needs for adults requiring end of life care, 2010, http://www.gmecscn.nhs.uk/attachments/article/99/HCA_guide.pdf

23. Grant RW, Ashburner JM, Hong CS, et al. Defining patient complexity from the primary care physician's perspective: a cohort study. *Ann Intern Med* 2011; 155: 797–804.

24. Kannampallil TG, Schauer GF, Cohen T, et al. Considering complexity in healthcare systems. *J Biomed Inform* 2011; 44: 943–947.

25. Levula AV, Chung KSK, Young J, et al. Envisioning complexity in healthcare systems through social networks. In: Proceedings of the IEEE/ACM international conference on advances in social networks analysis and mining, Niagara Falls, ON, Canada, 25–28 August 2013, pp. 931–936. New York: ACM.

26. Safford MM, Allison JJ and Kiefe CI. Patient complexity: more than comorbidity. The vector model of complexity. *J Gen Intern Med* 2007; 22: 382–390.

27. Shippee ND, Shah ND, May CR, et al. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *J Clin Epidemiol* 2012; 65: 1041–1051.

28. Simon TD, Cawthon ML, Stanford S, et al. Pediatric medical complexity algorithm: a new method to stratify children by medical complexity. *Pediatrics* 2014; 133: e1647–e1654.

29. Weinberger H, Cohen J, Tadmor B, et al. Towards a framework for untangling complexity: the interprofessional decision-making model for the complex patient. *J Assoc Inf Sci Tech* 2015; 66: 392–407.

30. Zullig LL, Whitson HE, Hastings SN, et al. A systematic review of conceptual frameworks of medical complexity and new model development. *J Gen Intern Med* 2016; 31: 329–337.

31. Zulman DM, Asch SM, Martins SB, et al. Quality of care for patients with multiple chronic conditions: the role of comorbidity interrelatedness. *J Gen Intern Med* 2014; 29: 529–537.

32. Tuca A, Gomez-Martinez M and Prat A. Predictive model of complexity in early palliative care: a cohort of advanced cancer patients (PALCOM study). *Support Care Cancer* 2017; 26: 241–249.

33. National Audit Office (NAO). *End of life care*. London: The Stationery Office, 2008.

34. National Casemix Office and Health and Social Care Information Centre. *Casemix companion*. London: Health and Social Care Information Centre, 2016.

35. Jay N, Nuemi G, Gadreau M, et al. A data mining approach for grouping and analyzing trajectories of care using claim data: the example of breast cancer. *BMC Med Inform Decis Mak* 2013; 13: 130.

36. Averill RF, Muldoon JH, Vertrees JC, et al. *The evolution of casemix measurement using diagnosis related groups (drgs)*. Wallingford: 3M Health Information Systems, 1998.

37. Fetter RB. Casemix classification systems. *Aust Health Rev* 1999; 22: 16–34.

38. France FH. Case mix use in 25 countries: a migration success but international comparisons failure. *Int J Med Inform* 2003; 70: 215–219.

39. Schmid A, Cacace M, Götze R, et al. Explaining health care system change: problem pressure and the emergence of 'hybrid' health care systems. *J Health Polit Policy Law* 2010; 35: 455–486.

40. Lee LA, Eagar KM and Smith MG. Subacute and non-acute casemix in Australia. *Med J Aust* 1998; 169: S22–S25.

41. Eagar K, Cromwell D, Kennedy C, et al. Classifying subacute and non-acute patients: results of the New South Wales Casemix area network study. *Aust Health Rev* 1997; 20: 26–42.

42. Turner-Stokes L, Sutch S, Dredge R, et al. International casemix and funding models: lessons for rehabilitation. *Clin Rehabil* 2012; 26: 195–208.

43. Eagar K, Gordon R, Green J, et al. An Australian casemix classification for palliative care: lessons and policy implications of a national study. *Palliat Med* 2004; 18: 227–233.

44. Mather H, Guo P, Firth A, et al. Phase of Illness in palliative care: cross-sectional analysis of clinical data from community, hospital and hospice patients. *Palliat Med*. Epub ahead of print 1 August 2017. DOI: 10.1177/0269216317727157.

45. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health C* 2007; 19: 349–357.

46. Robinson OC. Sampling in interview-based qualitative research: a theoretical and practical guide. *Qual Res Psychol* 2014; 11: 25–41.

47. Huberman AM and Miles MB. *The qualitative researcher's companion*. Thousand Oaks, CA: SAGE, 2002.

48. Ritchie J and Lewis J. *Qualitative research practice: a guide for social science students and researchers*. London: SAGE, 2003.

49. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013; 13: 117.

50. NatCen. *The framework approach to qualitative data analysis*. London: NatCen, 2012.

51. Department of Health. *NHS Patient experience framework*. London: Department of Health, 2012.

52. National Research Council. *Dynamic social network modeling and analysis: workshop summary and papers*. Washington, DC: National Academies Press, 2003.

53. World Health Organization (WHO). Framework on integrated people-centred health services, http://www.who.int/servicedeliverysafety/areas/people-centred-care/framework/en/ (accessed 12 November 2017).

54. Bronfenbrenner U. Ecological models of human development. In: Gauvain M and Cole M (eds) *Readings on the development of children*. 2nd ed. New York: W. H. Freeman and Company, 1994, pp. 37–43.

55. Saunders C. Care of patients suffering from terminal illness at St Joseph's Hospice, Hackney, London. *Nursing Times*, February 1964, pp. 1031–1032.

56. Saunders C. The symptomatic treatment of incurable malignant disease. *Prescribers J* 1964; 4: 68–73.

57. World Health Organization (WHO). *The global burden of disease: 2004 update*. Geneva: World Health Organization, 2004.

58. Wen-ying SC, Anna G and Alexander P. Health literacy and communication in palliative care. In: Wittenberg E, Ferrell BR, Goldsmith J, et al. (eds) *Textbook of palliative care communication*. Oxford: Oxford University Press, 2015.

59. Monroe B and Oliviere D. *Resilience in palliative care: achievement in adversity*. Oxford: Oxford University Press, 2007.

60. Ellershaw J and Ward C. Care of the dying patient: the last hours or days of life. *Br Med J* 2003; 326: 30–34.

61. McCorkle R, Ercolano E, Lazenby M, et al. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 2011; 61: 50–62.

62. Strömgren AS, Groenvold M, Pedersen L, et al. Does the medical record cover the symptoms experienced by cancer patients receiving palliative care? A comparison of the record and patient self-rating. *J Pain Symptom Manage* 2001; 21: 189–196.

63. Janse AJ, Gemke RJ, Uiterwaal CS, et al. Quality of life: patients and doctors don't always agree: a meta-analysis. *J Clin Epidemiol* 2004; 57: 653–661.

64. Addington-Hall J. Research sensitivities to palliative care patients. *Eur J Cancer Care* 2002; 11: 220–224.

65. Firn J, Preston N and Walshe C. What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis. *Palliat Med* 2016; 30: 240–256.

66. Masso M, Allingham SF, Banfield M, et al. Palliative care phase: inter-rater reliability and acceptability in a national study. *Palliat Med* 2015; 29: 22–30.

67. Eagar K. The Australian national sub-acute and non-acute patient casemix classification. *Aust Health Rev* 1999; 22: 180–196.