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Exploring the transition from curative care to palliative care: A systematic review of the literature

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Abstract

Background: UK policy guidance on treatment and care towards the end of life identifies a need to better recognise patients who are likely to be in the last 12 months of life. Health and social care professionals have a key role in initiating and managing a patients' transition from 'curative' care to palliative care. The aim of this paper is to provide a comprehensive and systematic review of the evidence relating to the transition from curative care to palliative care within UK settings.

Method: Four electronic databases were searched for studies published between 1975 and March 2010. Inclusion criteria were all UK studies relating to the transition from curative care to palliative care in adults over the age of 18. Selected studies were independently reviewed, data was extracted and quality was assessed according to predefined criteria.

Results: Of the 1464 articles initially identified, 12 papers met the criteria for inclusion. Four themes emerged from the literature: (i) patient and carer experiences of transitions; (ii) recognition and identification of the transition phase; (iii) optimising and improving transitions; (iv) defining and conceptualising transitions.

Conclusions: The literature suggests that little is known about the potentially complex transition from curative care to palliative care. Evidence suggests that continuity of care, and multidisciplinary collaboration are crucial in order to improve the experience of patients making the transition. An important role is outlined for generalist providers of palliative care. Incorporating palliative care earlier in the disease trajectory and implementing a phased transition appear key components of optimum care.

Background

Recent UK policy guidance on treatment and care towards the end of life care states that patients who are approaching the end of their life need high-quality treatment and care that support them to live as well as possible until they die. A key recommendation is that death should become an explicit discussion point when patients are likely to die within 12 months [1]. The End of Life Care Strategy for England also identifies a need to better recognise patients who are likely to be in the final 12 months of life, and identifies a key role for health and social care professionals in helping patients to come to terms with the transition from 'curative care' (with a focus on cure or chronic disease management), to end of life or palliative care [2]. While these policy initiatives identify a need to improve the transition from curative care to palliative care, there are currently no UK guidelines which specifically address this issue or provide guidance for the optimal management of this transition.

Facilitating a transition to palliative care remains a key clinical challenge, however little is known about this potentially complicated period [3]. The transition to palliative care can be a confusing and traumatic time for patients' and their families, and the transition may trigger fears of helplessness and abandonment [4]. For some the transition encompasses disruption in established healthcare services combined with uncertainty regarding the future. A Healthcare Commission Report in 2007 reported that often the decision to move from 'curing to caring' was not well communicated, leading to needless interventions that reduced a patients quality of life [5]. Whilst traditionally a sharp transition point has signalled the beginning of palliative care, more recent therapeutic models have described an approach incorporating gradual transitions, emphasizing palliative input and quality of life considerations during the active phase [6]. A phased transition or simultaneous care approach recognises that treatment goals evolve, and that concurrent active and palliative care may be most appropriate [7]. A phased transition may be particularly relevant for patients with non-cancer conditions, where the trajectory of decline is both unpredictable and highly variable [8].

Significant barriers have been identified which contribute to difficulties managing the transition to palliative care. A lack of certainty regarding when palliative care should begin can lead to difficulties in identifying when it is best to discuss palliative care with a patient [9]. The End of Life Care Strategy also acknowledges that definitions of the beginning of palliative care vary considerably according to individual patient and professional perspectives, and this has implications for timing the transition [2]. A scoping review by

Marsella (2009)[3] identified three key elements which complicate the transition to palliative care. Firstly the nature of the transition and what it means to patients. Secondly transitions can be difficult because of a lack of time to appropriately prepare patients and families. Lastly, a lack of information regarding the goals of palliative care can lead to confusion and complications [3]. Schofield et al (2006) [10] undertook a literature review as the basis for outlining steps for facilitating the transition to palliative care. Whilst these steps provide useful recommendations, the authors acknowledge a paucity of research in the area and fail to address the impact of variations in health care systems and resources in cross-national literature. In addition other authors have identified problems with these guidelines and recommend further clarifications and reflections around this difficult transition [11].

Evidence also suggests a lack of concordance with respect to triggers indicating the appropriateness of a transition to palliative care. Whilst policy guidelines advocate the use of the ‘12 months’ question as an indicator that patients may require palliative care input, recent evidence suggests this question may not be appropriate for patients with non-cancer diagnoses [12]. The Gold Standards Framework suggests the use of a prognostic indicator guide to identify patients predicted to be in the final 6-12 months of life who might be in need of palliative care [1]. Whilst in general the GSF has been well received, implementation is variable and the direct impact on patients and carers is not known [14]. In addition the GSF was developed for primary care, and whilst it has now been implemented in care homes, a parallel framework for use in secondary care has not yet been developed or validated. The transition to palliative care remains ill defined and under- researched. Current UK policy fails to offer guidance or recommendation for the optimisation of the transition, despite highlighting a need to better recognise and manage the changing goals of care. This paper aims to explore the evidence relating to transitions to palliative care within a UK context, through a systematic review of the literature. In doing so it seeks to add to the limited body of research surrounding the transition from curative care to palliative care.

Methods

A systematic review of qualitative and quantitative literature was undertaken to explore evidence relating to transitions to palliative care in the UK. The review was undertaken in the following five stages: (1) search strategy; (2) inclusion criteria; (3) assessment of relevance; (4) data extraction and appraisal; (5) data synthesis.

Search strategy

The aim of the search was to identify a comprehensive list of published papers which met predefined inclusion criteria. Keywords were identified and relevant databases were selected and searched in consultation with a health care information management specialist based at The School of Health & Related Research (ScHARR) at The University of Sheffield. The databases: Medline; EMBASE; CDSR; and NHSEED were searched for literature published between 1975 and March 2010. The following journals were hand searched for relevant articles: *Palliative Medicine; Journal of Palliative Care; Supportive Care in Cancer; Journal of Advanced Nursing*. Relevant references from bibliographies and through citation indices were followed up.

Inclusion criteria

Inclusion criteria were developed by consensus within the research team. Literature had to refer to the transition from active or curative care, to care incorporating a palliative approach. Literature also had to refer to an adult population (over the age of 18 years) and be UK based (since variations in health care systems and resourcing worldwide mean that the relevance of international papers to the UK is likely to be limited). All types of published literature were eligible for inclusion. Keywords comprised: ‘palliative care’, ‘terminal care’, ‘end of life care’, ‘hospice care’, ‘supportive care’, ‘transition’, and ‘continuity’. Appropriate wildcards were inserted to search for word ending truncations where necessary.

Assessment of relevance and evaluation of quality

Study selection was conducted in a systematic sifting process over three stages: title, abstract and full text. At each stage studies were rejected that definitely did not meet the inclusion criteria. Each paper was independently assessed by CG and one of the other authors (CI, MG or TR); in cases where there was disagreement between researchers, consensus was reached by discussion. As it was anticipated that a range of papers using different research methods would be obtained, traditional Cochrane study design criteria to weight studies were not used. Instead, the review was conducted using a method for systematically and objectively reviewing research from different paradigms, devised by Hawker et al. (2002) [15]. This method was deemed most appropriate as it was expected that the review would identify both qualitative and quantitative research papers.

Data extraction, appraisal, and synthesis

A checklist adapted from Hawker et al. (2002)[15] was used to extract and appraise data on: abstract & title; introduction and aims; methods and data; sampling; data analysis; bias; results; transferability or generalisability; implications and usefulness. Quality assessment was achieved by calculating a score for each paper based on an individual score for each item on the checklist. Scores ranged from 9 (very poor) to 36 (good) and indicate the methodological rigour for each paper. As each paper was assessed by two researchers, a mean sore for each paper was calculated. Owing to the diverse nature of the included studies, statistical synthesis or analysis of study findings was not appropriate.

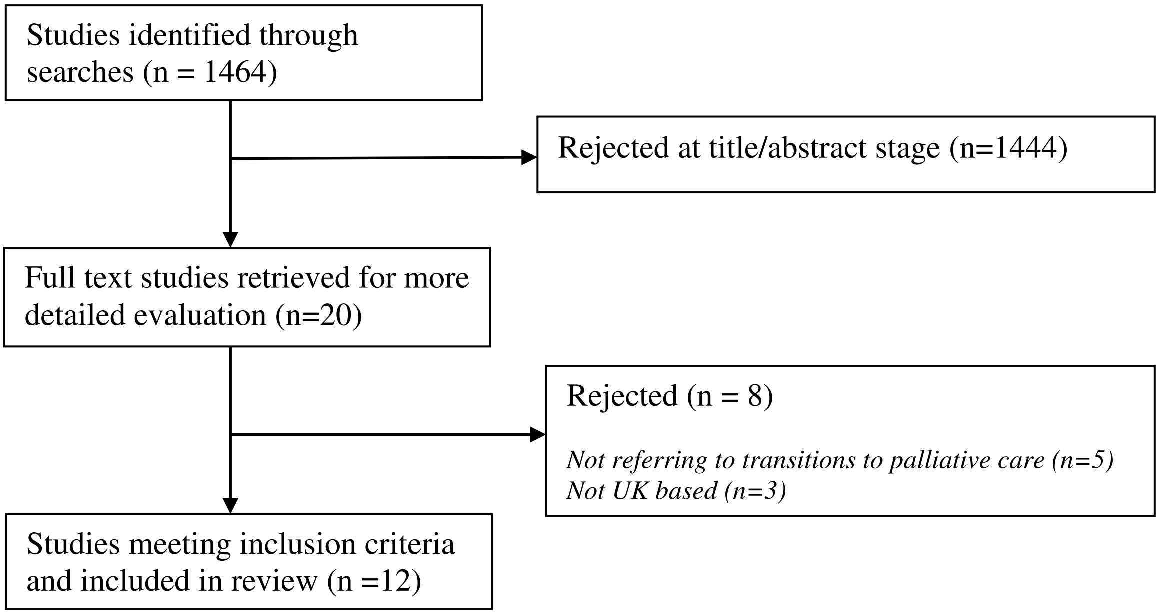

Figure 1: Flow chart of included literature

Results

Of 1464 citations initially identified, 12 articles (relating to 11 studies) met the inclusion criteria. Articles that were excluded (n = 1452) were not relevant to the research aim or were not UK papers (figure 1). One paper included both UK and European data and was included. Eight of the included articles were qualitative studies of patients, carers or health professionals. One study was a mixed methods comparative cohort study, one a case study report, one a critical discourse analysis, and one a non-empirical discussion piece. Transitions to palliative care were the main focus in only two of the included papers [16, 17], the remainder referred to transitions only as a minor theme or as a component of the discussion. The majority of empirical papers involved patients with cancer diagnoses, five papers related to cancer alone, four papers related to both cancer and non-cancer conditions. One study did not provide details of patient diagnoses, and two studies were non-empirical. Most papers scored satisfactorily on assessment of methodological rigour with no paper scoring less than 28 out of a maximum 36. One paper could not be scored as it was a non-empirical discussion piece. Details of the 12 papers and assessment scores are provided in table 1.

The results of the review are presented in terms of a summary and evaluation of the literature in relation to the research aim. The evidence can be grouped into four main themes (i) patient and carer experiences of transitions, (ii) recognition and identification of the transition phase, and criteria for making transitions (iii) optimising and improving transitions, (iv) defining and conceptualising transitions.

Patient and carer experiences of transitions

Of the papers included in the review, nine provided evidence or discussion of patient and carer experiences of transitions. The overwhelming consensus was of fear and uncertainty when making the transition to palliative care. Larkin [16,17] reported how cancer patients described a variety of emotional responses reflecting fears and losses. Patients found transitions confusing due to mixed messages, poor communication and uncertainty. They described having limited knowledge about the purpose and timing of transitions, uncertainty about who instigated the transition, limited involvement in decision-making and, once transferred to palliative care services, a sense of waiting for something to happen. Patients also reported that hospitals can provide unrealistic information about the level of service available for patients upon transitioning to palliative care. This finding resonated with health professionals who reported patient's expectations may be unrealistic regarding care that can be delivered [18].

Patient concerns were also identified in a qualitative study of lung cancer patients who reported they felt particularly unsafe in periods between curative treatment and follow-up appointments. They also felt ill-prepared for discharge from curative care, and detected inadequacies in inter-professional communication [19]. Communication was also highlighted as an important issue in a qualitative interview study of patients receiving specialist palliative care [20]. Patients in this study described uncertainties about the extent and nature of inter and intra-professional communication, and described having to relay information themselves between different professionals involved in their transitioning care. The importance of continuing care was frequently apparent in the literature. Patients and carers described continuity of care as a key component for improving the experience of transitions to palliative care [18, 20, 21]. Continuity appears critical to satisfaction with care and services, however it is clear that complexities may occur and continuity may be disrupted when many agencies are involved in providing care for an individual [18]. Whilst the majority of papers focused on patients with cancer conditions, a study by Murray [22] compared the needs of cancer and heart failure patients in the last year of life. They identified that cancer patient reported heightened distress at particular transition points, including after curative treatment ceases. However, psychological and social decline in heart failure patients mirrored the physical decline rather than reacting to particular transitions.

Recognition and identification of transition phase

Recognition of the palliative transition phase by health and social care professionals was identified as an important factor for facilitating optimum care [23, 16, 21]. O'Leary [23] reported that an early recognition of the palliative transition point was key to ensuring end of life issues were addressed. In a study by Bestall [21], primary care professionals described how late recognition of palliative care need and referrals at a late stage could have a negative impact on patients, and their relatives during bereavement. However it was acknowledged that a clear cut transition to a palliative care approach was rare. Particular challenges exist when identifying the transition in non-cancer conditions such as heart failure, where the episodic nature of the condition can lead to a delayed recognition of the palliative transition [23].

Two papers discussed transitions in relation to critical care settings [24, 25] and discussed the difficulties of integrating palliative care into critical care. The papers highlight that a transition should not emphasize a dichotomy between cure and palliative care. Within the critical care setting patients can deteriorate very quickly and the transition from curative to palliative may be rapid [24]. In addition transitions to palliative care within critical care are often discussed within the context of a transition in physical location, thus defining a very definite transition point. It is acknowledged that dying in critical care may infringe dignity, and a timely recognition and implementation of a palliative care transition is essential for maintaining dignity [25].

Four papers made suggestions for criteria to identify the transition to palliative care. O'Leary [23] listed factors defining the palliative transition point in heart failure, these include:

deterioration despite optimum support; increasing fatigue or functional dependence; low ejection fraction; recurring hospitalisations; emotional distress; carer fatigue; and patient request. Bestall [21] explored reasons for referral to specialist palliative care for both cancer and non-cancer conditions and highlight a lack of standardised criteria in the UK to determine when a referral should be triggered. Referral criteria identified in this study included complex symptoms, problems with medication side-effects, complex social or practical issues, carer burnout, and emotional distress. Health professionals discussed using referral criteria such as the Leeds Eligibility Criteria or locally developed guidelines, but most would have liked further guidance about when and how to refer patients to specialist palliative care [21]. Cancer patients interviewed in a study by Larkin [16] described how a rapid deterioration resulting in loss of independence was a primary reason for a transition to palliative care. Some respondents reported that a decision to move to palliative care was based on an evaluation of their potential burden to others rather than personal choice. Within the critical care setting, guidelines for the recognition of a palliative transition are rather broader and include the patient 'no longer benefitting from critical care', patient and family request, and the views of family and health professionals [24].

Optimising and improving transitions

The majority of studies acknowledged that the transition to palliative care could be improved. As early as 1978 researchers identified the importance of continuing care after the cessation of active treatment [26]. However, only four papers made any specific recommendations or developed any guidelines for improving the transition. O'Leary [23] discussed how the optimum transition should encompass planned and integrated transfer of patient information, the reiteration of patient preferences and the renegotiation of care goals. Recognition of the transition point was identified as key in order that a collaborative care plan can be established, ensuring the most appropriate level of care. In addition improvements to services such as respite and out of hours care were also identified as a requirement for optimum transitions [18]. Kendall [27] developed recommendations for the care of patients with cancer in primary care after discussion with patient groups. Patients and carers outlined an important and unique role for primary care staff throughout the cancer trajectory. Continuity of care and an individualised approach were considered crucial to driving patient centred care forwards. Recommendations given for managing the recurrence of cancer and the last weeks included letting patients express their concerns, helping with social and practical issues, respecting patients value and choices and supporting carers, frequently reviewing and coordinating care, and being flexible and responsive. Continuity of care was also highlighted as a crucial factor by patients and staff in a study by Patrick [18]. Continuity appeared critical to overall satisfaction and was particularly important during the transition when many agencies were involved in an individual package of care [18]. Researchers in critical care also identified individualised assessment as important, and again highlighted a need for comprehensive collaboration [25]. Whilst it is acknowledged that transitions in critical care may be very different to transition in other care settings, many of the care goals and recommendations are similar.

Defining and conceptualising transitions

Defining the concept of a transition to palliative care remains a challenge. In healthcare, transitions may include changes in the place of care, the care-giver, or the goals of care. However transition in the palliative care literature goes further than just change in place or caregiver, it also relates to the personal meaning of life, life/role changes, perceptions of end of treatment, and likelihood of death. Understanding the concept of this transition is necessary for facilitating end of life care [23]. A study by Larkin [16] explored the experiences and meaning of transition for a group of palliative care patients. Whilst they reported that the successful merging of the curative-palliative interface was beneficial for patients, they suggest the concept of transition warrants further investigation. In particular they raised concerns that transition concepts fail to capture the palliative care experience fully. Transition literature often describes overtly positive outcomes such as resilience, reconstruction, coherence, life purpose, sense of self, transcendence and transformation. However interview data from patients does not always fit with these descriptions [16,19, 22]. Transience is suggested as an alternative concept and is further explored in a second study [17]. Transience depicts a more fragile emotional state and is proposed as a more meaningful concept for palliative care when compared to current conceptualisations of transition as a process towards resolution. It is acknowledged that transience remains an emerging concept, and further conceptual development is required.

Discussion

Recent UK policy has stressed the importance of managing and facilitating the transition from curative care to palliative care [1, 2]. This review of the literature suggests that within a UK context, little is known about this potentially complex transition, and literature relating to the optimisation of the transition is sparse. Shortcomings in the literature mean we are unable to provide strong empirical evidence to support practice and policy recommendations. Only two of the included papers had a primary focus on transitions to palliative care [16, 17]. There were no randomised controlled trials or intervention studies. The majority of papers were qualitative studies with three of the papers descriptive or discursive pieces.

Despite these limitations this review identifies issues of significant importance which warrant further research and discussion. It is clear that the transition to palliative care can be a confusing and distressing time for patients and their families. The experience of the transition can leave patients and their families feeling abandoned, and lacking a clear understanding of their future care and treatment options [16, 18, 19, 27]. The findings from this review resonate with research from outside the UK citing challenges surrounding the nature of the transition from the patient perspective [3]. Facilitating a sensitive transition is therefore imperative for improving the experiences of patients and their families at this difficult time.

Evidence suggests that continuity of care is crucial to achieving a sensitive and well managed transition [18, 20, 21]. A particular issue with the transition to palliative care is that traditionally it has been defined in terms of a very sharp transition point accompanied by a multitude of changes including physical location, care providers, and care goals. Achieving continuity of care throughout these changes is a key challenge which must be overcome before the patient experience of the transition to palliative care can be optimised. An emphasis of UK strategies is on improving palliative care delivered by generalist providers (primary care teams, hospital staff, social care services) [1, 28]. Generalist providers, often with long standing relationships with patients, are well placed to provide high quality palliative care, whilst retaining continuity of care. Whilst a proportion of patients will continue to have complex needs requiring the input of specialist palliative care teams, continued support from generalist providers is crucial to ensuring patients do not feel abandoned during this difficult transition.

Managing the transition to palliative care earlier can also affect how, and potentially where people die. However what constitutes ‘palliative care’ is not uniformly understood and opinions vary as to who is a ‘palliative care’ patient [28]. The current review identified only four papers which include suggested criteria for identifying the transition to palliative care, and none have received formal validation [16, 20, 23, 24]. Further indicators have recently been proposed by Boyd & Murray [28], taking into account a review of prognostic models and guidelines. They propose that clinical judgement informed by evidence, rather than more refined prognostic accuracy, is the key to an earlier identification of patients with palliative care need. There is a clear need for further formal validation of proposed indicators. Internationally developed indicators such as the US National Hospice and Palliative Care Organisation tool should also be considered, however the organisation and resourcing of palliative care services in the US and elsewhere may define a sharper transition to palliative care accompanied by an immediate cessation of curative care, thus reducing the appropriateness of US models for a UK health care system.

Recommendations for optimising or improving the transition to palliative care are similarly sparse, despite recognition that the transition is often experienced poorly by patients and their families. A key challenge to optimising the transition is sensitively managing the often abrupt change in care provider, care location, and care goal that has traditionally accompanied a referral to specialist palliative care services. The abruptness of these changes can lead to patients and their families feeling confused and abandoned, and recommendations highlight a need for collaborative working and continuity of care during the transition[18, 23, 27]. Support from specialist palliative care services and close collaborative working between care providers is necessary in order that patients with need for palliative input are identified, whilst disease modifying treatments continue [27]. In order for this to be achieved the significant barriers that have been identified to clinicians discussing issues relating to end of life care with 'non-cancer' patients will need to be addressed[29,30] .

Many patients may stand to benefit from better identification, assessment, and management of the transition to palliative care. Optimal management may provide patients and their families with opportunities for addressing preferences for care, and could mitigate the uncertainty and helplessness that currently surrounds this transition. Research is required to further explore these issues, particularly in light of evidence which suggests some patients may be reluctant to receive information relating to a poor prognosis or 'bad news' [31,32] . A phased transition incorporating palliative care in parallel with disease modifying treatments appears the most appropriate model for optimising transitions. This model is particularly relevant for patients with non-cancer disease whose conditions may be more slowly progressive or with fluctuating trajectories. Within this phased transition continuity of care and multidisciplinary collaboration are crucial to optimising care. An agreed consensus of definition, and potential refinements to the conceptualisation of the transition may also be necessary in order enhance consistency. Further research is required, taking into account UK policy and guidance, in order to maximise current resources and develop appropriate guidelines and care models for managing the transition from curative care to palliative care.

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Table 1: Details of included papers

Author & year	Aims	Participants	Setting	Method	Relevant findings
Bestall JC, Ahmed N, Ahmedzai S Payne S, Noble B, Clark D (2004).	To explore the reasons why patients and families are referred to specialist palliative care (SPC) **Assessment score = 31**	13 patients referred to SPC (cancer and non-cancer diagnoses), 12 professionals working in SPC, 3 GP's, 6 community nurses	North Trent Cancer Network, England	Qualitative semi-structured interviews and content analysis.	Five key themes reported: reasons for/against referral to SPC, timeliness of referrals, continuity of care, use of referral criteria. Currently no standardised criteria in the UK to determine when a referral to SPC should be triggered. Referral criteria outlined and include complex symptoms, use of referral guidelines. Development of referral criteria may aid transition to SPC.
Jarrett N (2009)	To investigate patients perceptions of intra-professional communication in an SPC setting. **Assessment score = 32**	22 patients receiving specialist palliative care input (21 cancer patients & 1 multiple sclerosis patient).	Two specialist palliative care units, England.	Qualitative in-depth interviews, grounded theory analysis of transcripts.	Patients largely positive about IIPC when it occurred, some uncertain about extent and nature of IIPC, some patients described relaying information between different professionals or care locations, some patients and families very proactive to enhance IIPC and continuity of care.
Kendall M, Boyd K, Campbell C et al. (2006).	To involve patients with cancer, and their carers, in designing a framework for providing effective cancer care in primary care. **Assessment score = 32**	18 patients/carers with cancer & 16 professionals involved in cancer care.	South-east and south-west of Scotland	Action research model involving two patient/ carer discussion groups who met monthly over a year, and interviews with professionals.	Five key points during cancer trajectory have particular significance: diagnosis; treatment; after discharge; recurrence; the final weeks. Important role for primary care acknowledged throughout cancer trajectory. Support from primary care beneficial during transition from remission to recurrence to final weeks. Continuity of care and an individualised approach are crucial.
Krishnasamy M, Wells M, Wilkie E. (2007)	To explore patients and family members experiences of care provision after a diagnosis of lung cancer. **Assessment score = 31**	23 lung cancer patients and 15 carers.	Tayside, Scotland	Qualitative in-depth longitudinal interview study involving 3 interviews over a 6 month period.	Four key domains of need apparent (1) pathway to confirmation of diagnosis; (2) communication of diagnosis, treatment options, prognosis; (3) provision of coordinated care; (4) support away from acute services including difficulties transitioning between services. Patients felt particularly unsafe in periods in between treatment and

					follow up appointments, they felt ill-prepared for discharge or detected inadequacies in primary/secondary care communication. Many patients relied on relationship with their hospital consultant and found it difficult transitioning into palliative care.
Larkin PJ, Dierckx-de-Casterle B, Schotsmans P (2007[a]).	To document palliative care patients experience at the palliative/terminal interface; to identify perceived supportive and inhibitory factors; to analyze common experiences in the context of current palliative care development in European terms as a means to inform practice. **Assessment score = 30.5**	100 advanced cancer patients	Palliative care centres in six European countries (UK, Ireland, Spain, Netherlands, Italy, Switzerland)	Phenomenological approach using semi-structured interviews.	Transition is a confusing time for patients due to mixed messages, poor communication & uncertainty, physical environment of the hospice offers a place of security to address this. Transition concepts fail to capture the palliative care experience fully & warrants further exploration. Transience is reported as an alternative concept, although more research is needed. Successful merging of curative/ palliative interface is beneficial to patients. Clinicians need to ensure a seamless transition as proposed as a key construct of palliative care.
Larkin PJ, Dierckx-de-Casterle B, Schotsmans P (2007[b]).	To support define and consolidate the emerging concept of transience and to critically appraise how far qualitative approaches fit the examination of transience as a concept and its potential importance to palliative care. **Assessment score = 28.3**	100 advanced cancer patients	Palliative care centres in six European countries (as above)	Qualitative conceptual evaluation using two case examples from interview data (see previous Larkin paper) and a critical review of the literature.	Transience is proposed as a preferred concept to transition in relation to palliative care. Transience encompasses attributes such as fragility, impermanence, and stasis which are not adequately explained by transition concept. More evidence is needed before transience can be described as a well defined and robust concept for palliative care but data from case studies supports concept of transience.

Murray S, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A (2007)	To identify and compare changes in psychological, social and spiritual needs of people with end stage disease during the last year of life. **Assessment score = 35.5**	24 patients with lung cancer (LC) and 24 with heart failure (HF)	Primary and secondary care in South-East Scotland.	Data synthesis from two longitudinal, qualitative in-depth interview studies. Thematic and narrative analysis of transcripts.	Characteristic social, psychological and spiritual trajectories were discernible. LC patients reported particular distress at transition points including after treatment - 'returning to their old life'. They also experienced difficulties at relapse/disease progression – for some engaging in a battle with the cancer gave them some sense of purpose. In terminal phase patients had overwhelming uncertainty, panic attacks etc. In HF, social and psychological deterioration ran in parallel with physical deterioration, and were mediated by this. Spiritual distress fluctuated more and was modulated by other factors.
O'Leary N, Murphy NF, O'Loughlin C, Tiernan E, McDonald K (2009).	To demonstrate whether the palliative care needs of patients with advanced heart failure (HF) receiving specialist multidisciplinary coordinated care are similar to cancer patients deemed to have specialist palliative care needs. **Assessment score =28.5**	50 HF patients (NYHA stage III/IV) and 50 cancer patients (newly referred to specialist palliative care)	Outpatient HF disease management clinic and specialist palliative care home service in England	Cross sectional comparative cohort study using quantitative and qualitative methods to explore functional status, symptom burden, emotional wellbeing, quality of life and information & communication needs.	HF and cancer patients similar in terms of symptom burden, emotional wellbeing and QOL. HF patients should not be excluded from SPC services, however many needs can be met at a specialist HF unit. Recognition of palliative transition point may be key to ensuring end of life issues are addressed. Various factors defining the transition point in HF are listed. Understanding the concept of transition can facilitate end of life care.
Patrick H, Taylor F, Schwenke M, Jones E (2007)	To learn about the quality of local services from the perspective of patients, carers and staff. To develop an appropriate methodology for future consultation. **Assessment score = 32**	10 palliative care service users/carers and 9 staff.	Palliative care services (hospice, community & hospital) in Kent, England.	Semi-structured interviews with patients and focus groups with staff. Content analysis of transcripts.	Continuity of care important and complex when many agencies involved in an individual package of care. Continuity critical to participants overall level of satisfaction with the service provided. Staff had concerns that patients expectations are beyond what they can deliver. Hospitals give unrealistic expectations about the level of service in the community e.g. out of hours and respite care

					services. More respite and out of hours medication services needed.
Pattison N (2006)	To explore written guidelines and documents for critical care as evidence for the provision of end of life (EOL) care in critical care. **Assessment score = 34.2**	N/A	UK	Critical discourse analysis of four key UK government critical care documents.	Little clear guidance about how to provide EOL care in critical care. Transitions to EOL care in critical care are often discussed within the context of a transition in physical location, this defines a very definite transition point. In addition patients can deteriorate very quickly and the transition from curative to palliative may be rapid. Dying in critical care may infringe dignity, transition away from interventions to comfort measures can improve dignity.
Pattison N (2004)	Discussion paper on the integration of critical care and palliative care at end of life. **No assessment score (non-empirical paper)**	N/A	UK	Discussion paper drawing from several literature sources.	Discussion of the difficulties faced when patients transition from curative treatment to palliative care. Transition must not emphasize a dichotomy between cure and palliative care. Nurses can potentially be excluded from decisions regarding a transition and may not be in control when the change of goal takes place. Transitions can be fragmented & comprehensive collaboration is required, patients must not be reduced to a prognostic probability. Consistent decision making is necessary but each patients case must be considered on its own circumstances.
Wills LAM (1978)	Case study summary of the first year of a Macmillan continuing care unit for patients with malignant disease. **Assessment score = 17.5**	71 cancer patients referred to the unit in its first year of opening.	Continuing care unit at an acute hospital in West Sussex, England.	Case study of routinely collected data.	The unit has the unique ability to coordinate with community and hospital based services. Importance of continuing care after cessation of active treatment acknowledged and achieved by regular home visits. As a consequence good relationships were built up, inpatient duration was reduced, and more effective episode care was made possible.