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**Patient, nursing and medical staff experiences and perceptions of the care of people diagnosed with palliative esophago-gastric cancer: A systematic review of the qualitative evidence**

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## **Executive summary**

### **Background**

Esophago-gastric cancer is the fifth most common malignancy and its incidence is increasing. The disease is fast paced and five year survival rates are poor. Treatment with palliative intent is provided for the majority of patients but there remains a lack of empirical evidence into the most effective service models to support esophago-gastric cancer patients.

### **Objectives**

The overall objective of this systematic review was to synthesize the best available evidence on the experiences and perceptions of patients and health professionals with regard to the care of people diagnosed with palliative esophago-gastric cancer.

### **Inclusion Criteria**

#### **Types of participants**

This review considered studies that included patients diagnosed with palliative esophago-gastric cancer and any health professionals involved in the delivery of palliative care to this patient group in a hospital, home or community setting.

#### **Phenomena of interest**

Studies that investigated the experience and perceptions of people diagnosed with palliative esophago-gastric cancer, and staff working with these people were considered.

#### **Context**

Studies that were carried out in any setting, including in-patient and out-patient areas, specialist cancer and non-specialist palliative care services and any patient in receipt or with experience of palliative care services were considered. All types of health practitioners delivering palliative care to esophago-gastric cancer patients were considered.

#### **Types of studies**

Studies that focussed on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, feminist research and narrative approaches were considered. Mixed methods studies were considered in the review only if qualitative findings were reported separately.

#### **Search strategy**

A three step search strategy was utilised. Eleven databases were searched for papers from 2000 onwards, followed by hand searching of reference lists.

### **Methodological quality**

Methodological quality was assessed using the Qualitative Assessment and Review Instrument critical appraisal tool (JBI-QARI) developed by the Joanna Briggs Institute.

### **Data extraction**

Qualitative findings were extracted using the Joanna Briggs Institute-Qualitative Assessment and Review data extraction Instrument (JBI-QARI).

### **Data synthesis**

Qualitative research findings were pooled using a pragmatic meta-aggregative approach.

### **Results**

This review included two publications. There were 46 findings which were aggregated into four categories and one overall synthesized finding: In addition to support for physical needs, patients needed support taking into account changing life situations to achieve the best quality of life.

### **Conclusions**

This review shows that patients value services and support that addresses their complex, fluctuating and highly individual needs. No evidence was uncovered regarding how these services should be designed and delivered.

### **Implications for practice**

Supportive care should take into account patients' holistic needs and offer the opportunity to talk about their experiences to make sense of their diagnosis and future. The physical, social and emotional implications of dysphagia should also be explored.

### **Implications for research**

Further research is needed to explore experiences and perceptions of care from a patient, staff and carer perspective, what models should look like and how these are delivered across hospital and community care.

### **Keywords**

Esophago-gastric cancer, health professionals, palliative care, patients, supportive care.

### **ConQual**

Confidence in the findings was assessed using the JBI ConQual approach, and deemed to be low.

**Table 1: ConQual Score**

Synthesised finding	Type of research	Dependability	Credibility	ConQual score
In addition to support for physical needs, patients needed support taking into account changing life situations to achieve the best quality of life	Qualitative	Downgrade 2 levels*	Downgrade 1 level**	Low

\*Downgraded two levels due to dependability issues in one study<sup>20</sup> (issues in justification of methodology, data collection and representation of data.)

\*\* Downgraded one level as mix of unequivocal and equivocal findings were included in the synthesised finding

## Background

Although esophago-gastric (EG) cancer is the fifth most common malignancy and fourth most common cause of cancer death in the United Kingdom (UK), affecting approximately 13,500 people each year,<sup>1, 2</sup> it has received less attention than other tumour sites (e.g. breast, lung and colorectal).

The incidence of EG cancer is increasing; specifically adenocarcinoma of the distal esophagus and gastro-esophageal junction<sup>3</sup> and the UK reports the highest incidence worldwide.<sup>4</sup> Key risk factors include tobacco smoking and high alcohol consumption (squamous cell carcinoma), gastro-esophageal reflux disease, Barrett's esophagus and obesity (adenocarcinoma). These risk factors are critical health issues affecting the UK population, in particular the alarming growth in alcohol consumption and obesity. However, due to the fast paced and progressive nature of the disease, it has a devastating impact on a patient's quality of life. Ensuring an effective and acceptable service for patients with EG cancer is therefore paramount.

The 5 year survival rate for patients who are diagnosed with localized EG cancer is 15%, The major reason for such poor survival rates is that patients are frequently diagnosed at advanced stages of their condition, thereby unsuitable for curative resections<sup>6</sup> so treatment with palliative intent is the model provided for the majority of patients, including palliative oncology, palliative surgery and

palliative care. Palliative care has also been identified as one of the worldwide public health priorities due to the ageing population.<sup>7</sup>

The World Health Organisation<sup>8</sup> published a framework for the development of national cancer control programmes, designed to provide guidance on what was feasible and desirable in terms of cancer prevention and management. In the UK the NHS Cancer Plan set out to improve cancer treatment within the National Health Service<sup>9</sup> providing a comprehensive strategy to bring together prevention, screening, diagnosis, treatment and care for cancer. The aim was to address inequalities in cancer care in the United Kingdom, to bring them in line with their European counterparts who had demonstrated improved survival rates for major cancer groups. The implementation of this ambition for those diagnosed with EG cancer was supported by the publication of Improving Outcomes Guidance in Upper Gastro-Intestinal Cancer<sup>10</sup> and Improving Supportive and Palliative Care for Adults with Cancer.<sup>11</sup>

Overall, there remains a lack of empirical evidence into the most effective service model(s) supporting palliative care for patients diagnosed with palliative EG cancer. Anecdotal evidence identifies inconsistent provision of palliative care support between services within and across primary and secondary care boundaries. For example, while a significant proportion of patients will receive palliative stent insertion, local experience suggests a need for greater clarity and coordination between services regarding follow-up and on-going support of the patient and family/carers in order to reflect the ambitions of best practice in cancer care.<sup>12</sup>

Despite the existence of national guidance, uncertainty remains about the most effective models of care for palliative care services, for example the National Institute for Care and Health Excellence (NICE) in the UK noted that: "*In particular, research is needed on the impact of comparisons between different ways of providing services, including careful measurement of outcomes important to patients and carers.*"<sup>11(p.32)</sup> This view has been echoed more recently in the UK, with regard to insufficient understanding of the experiences of patients and what they deem to be relevant individual and service-level outcome measures; issues that have also been identified as essential in providing high quality palliative cancer care.<sup>5</sup> In addition, the UK's NICE identifies the vital role of involving service users in service planning and orientating services around the issues faced by patients and families.<sup>11</sup>

Palliative care has been defined as:

*"The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families and many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments."*<sup>11(p.20)</sup>

Informed by the findings of a systematic review of studies aimed at improving supportive and palliative care for adults with cancer,<sup>13</sup> NICE reported that the body of existing research tended to focus on three main areas: *"the need for such care, its importance to those affected by cancer (and to society), and effective solutions."*<sup>11(p.168)</sup> The review found a wealth of evidence supporting the need for good supportive and palliative care among patients with cancer. However, although palliative and terminal care was among the top 15 health care priorities identified by members of the general public, the research evidence on effective solutions to meet these needs was deemed to be limited and requires further robust systematic investigation. NICE concluded that future research should aim to identify effective solutions, rather than reassessing need, including investigations into models that coordinate care, built on a full understanding of the experiences and expectations of those affected by cancer.<sup>11</sup>

Therefore, the authors believed that a systematic review of the qualitative evidence was required in relation to the care of patients receiving palliative treatment for EG cancer, in order to inform the planning, evaluation and delivery of services for this population group. This may also help to inform service provision for other people affected by cancer through sharing experiences and ways of managing the impact of cancer on their lives.<sup>11</sup> It is in this context that the requirement to undertake a systematic review of patient and health professionals experiences and perceptions of the care of people diagnosed with palliative esophago-gastric cancer became clear.

The review group examined the Cochrane Library, Prospero, JBI Database of Systematic Reviews and Implementation Reports, CINAHL and other relevant databases and did not find any current or planned reviews on the same topic. A meta-analysis of qualitative studies on esophageal and clinically similar forms of cancer was completed by Andreassen, Randers, Nyhlin et al.<sup>14</sup> and focussed on patients and family members' experiences of living with cancer, many of whom were still undergoing curative treatments for their cancer. It did not take into account experiences and perceptions of those specifically receiving palliative care, although a number of findings discussed in the study did shed light on such experiences. Three themes were formulated: "running into an unpredictable enemy", "enduring a fading body" and "entering social silence", where patients and family members described uncertainty and alienation against the patient's body, feelings of embarrassment, reluctance to socialise outside their home leading to feelings of isolation and loneliness. The authors concluded that both patients and their family members felt abandoned during their experiences as their unique, fluctuating and complex needs were not met by the models of health service provision offered. The participants in the studies were diagnosed with differing primary tumour sites such as head and neck, gastric and EG cancer and although clinically similar, they did not therefore address the specific objectives of this review.

## Objectives

The overall objective of this systematic review was to synthesize the best available evidence on the experiences and perceptions of patients and health professionals with regard to the care of people diagnosed with palliative EG cancer.

In meeting this objective, this review considered the following questions:

1. What are the expressed experiences and perceptions of patients and health professionals with regard to the care of people diagnosed with palliative EG cancer?
2. What do patients and health professionals believe are the most appropriate and acceptable ways to deliver care to people diagnosed with palliative EG cancer?
3. What do patients and health professionals believe influences achievement of the best quality of life for patients diagnosed with palliative EG cancer?

### **Inclusion criteria**

#### **Types of participants**

This review considered studies that included any participant involved in the delivery of palliative care to people diagnosed with palliative EG cancer in a hospital, home or community setting. Health professionals included nursing, medical and allied health professionals, including registered and non-registered health care practitioners (e.g. health care support workers).

The review also included studies of experiences and perceptions of patients diagnosed with palliative EG cancer aged 18 years or older.

Studies of experiences and perceptions of adult participants with potentially curative EG cancer or of those adults with curative treatment intent for EG cancer were excluded. Studies where the primary tumour site was not at the distal esophagus or gastro-oesophageal junction or those that had metastasized to this region were also excluded.

#### **Phenomena of interest**

The review considered studies that investigated the experience and perceptions of people diagnosed with palliative EG cancer and the staff working with these people. It also explored factors that patients and health professionals believed influenced achievement of the best quality of life for patients diagnosed with palliative EG cancer.

#### **Context**

This review considered studies that were carried out in any setting, including in-patient and out-patient areas, specialist cancer and non-specialist palliative care services and any patient or carer in receipt



or with experience of palliative care services. All types of health professionals delivering palliative care to non-curative EG cancer patients were considered for review.

### **Types of studies**

This qualitative review considered studies that focussed on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, feminist research and narrative approaches. Mixed methods studies were considered in the review only if qualitative findings were reported separately.

### **Search strategy**

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. Databases were searched from March to June 2015 and the last date databases were searched was 16 June 2015.

Studies published from the year 2000 onwards to coincide with the publication date of the NHS Cancer Plan<sup>7</sup> were considered for inclusion in this review. Whilst the NHS cancer plan was primarily developed to address inequalities in cancer survival rates in the UK, it was a seminal piece of legislation which sought to draw together models of care and service provision that addressed the whole of the cancer journey from screening, diagnosis, treatment, support, survival and palliative care services. No studies were found prior to the year 2000 that addressed this reviews main objectives.

The databases searched included:

- MEDLINE
- CINAHL
- EMBASE
- AMED
- PsycINFO
- PsycARTICLES
- Pubmed
- NICE (UK)
- ASSIA
- British Nursing Index (via ASSIA)
- MedNar

The search for unpublished studies included:

- PAIS International – grey literature/index to thesis MEDLINE
- The Christie Research Publication Repository
- Medical Research Council online MRC Research portfolio
- Health Services Research Projects in progress database (Via National Information Centre on Health Services research and Health care technology)

The Initial keywords used are presented in table 2.

<b>Key Concept</b>	<b>Synonyms/related terms</b>
Population	Esophago-gastric cancer/s (and its variants: Esophago-gastric tumor/s, Esophago-gastric neoplasm/s) Gastro-esophageal junction cancer/s (and its variants Gastro-esophageal junction tumor/s, Gastro-esophageal junction neoplasm/s)
Intervention & process	Palliative care (and its variants: Phase of palliation, Palliative phase/s, Palliative approach/s) Palliative treatment intent (and its variants: Palliative treatment/s, Palliative therapy/ies, Palliative intervention/s, Symptom palliation, Palliative chemotherapy, Palliative radiotherapy, Palliative surgery, Palliative endoscopy, Palliative stent/s, Supportive palliative care, Supportive care) No active treatment/s (and its variants: Non curative treatment/s, best supportive care, Ease burdensome symptoms).

**Table 2: Initial search keywords**

The full search strategy is provided in Appendix I.

## **Method of the review**

### **Study records and selection process**

After searching of the above named databases, all citations were exported into EndNote (Thomson Reuters). Duplicates were removed and then two independent reviewers (AC and CE) assessed titles and abstracts against the inclusion criteria. A study screening sheet was used to facilitate this process. Any disagreements were resolved by discussion between the authors with recourse to a third author (FBH) for arbitration where necessary. The latter, however, was not required.

Full papers were obtained for the studies labelled as included and uncertain and again, these papers were screened against the inclusion criteria. Any disagreements were resolved by discussion between the authors.

### **Assessment of methodological quality**

Qualitative papers selected for retrieval were assessed by two independent reviewers (AC and CE) for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II) after which, the reviewers met to discuss the results of the appraisal. Any disagreements that arose between the reviewers were resolved through discussion.

### **Data Extraction**

Qualitative data were extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix III). The data extracted included specific details about the phenomenon of interest, interventions, populations, study methods and outcomes of significance to the review question and specific objectives

Two team members (AC and CE) read each paper several times to obtain an overall understanding of the studies key themes, findings and clinical implications enabled them to be contextualised to the reviews objectives. One team member (AC) extracted the findings from the included studies, reported as themes, meaning structures and frames. Each extracted finding was supported by a verbatim data excerpt from the studies' research participants to demonstrate its meaning. Extracted findings can be found in appendix VII. Where this was not possible, the author's narrative was extracted. Findings were then reviewed and assigned levels of credibility; unequivocal, credible and unsupported, following the JBI guidelines.

- Unequivocal (U): Findings that were accompanied by illustrations that were beyond reasonable doubt and therefore not open to challenge
- Credible (C): Findings were accompanied by illustrations that lacked a clear association and were therefore open to challenge
- Unsupported (US): Findings not supported by data

These findings were reviewed jointly by AC and CE and assigned levels of credibility were agreed. Unsupported findings are displayed in appendix VII but not included in the final synthesis as these findings were not supported by credible data.

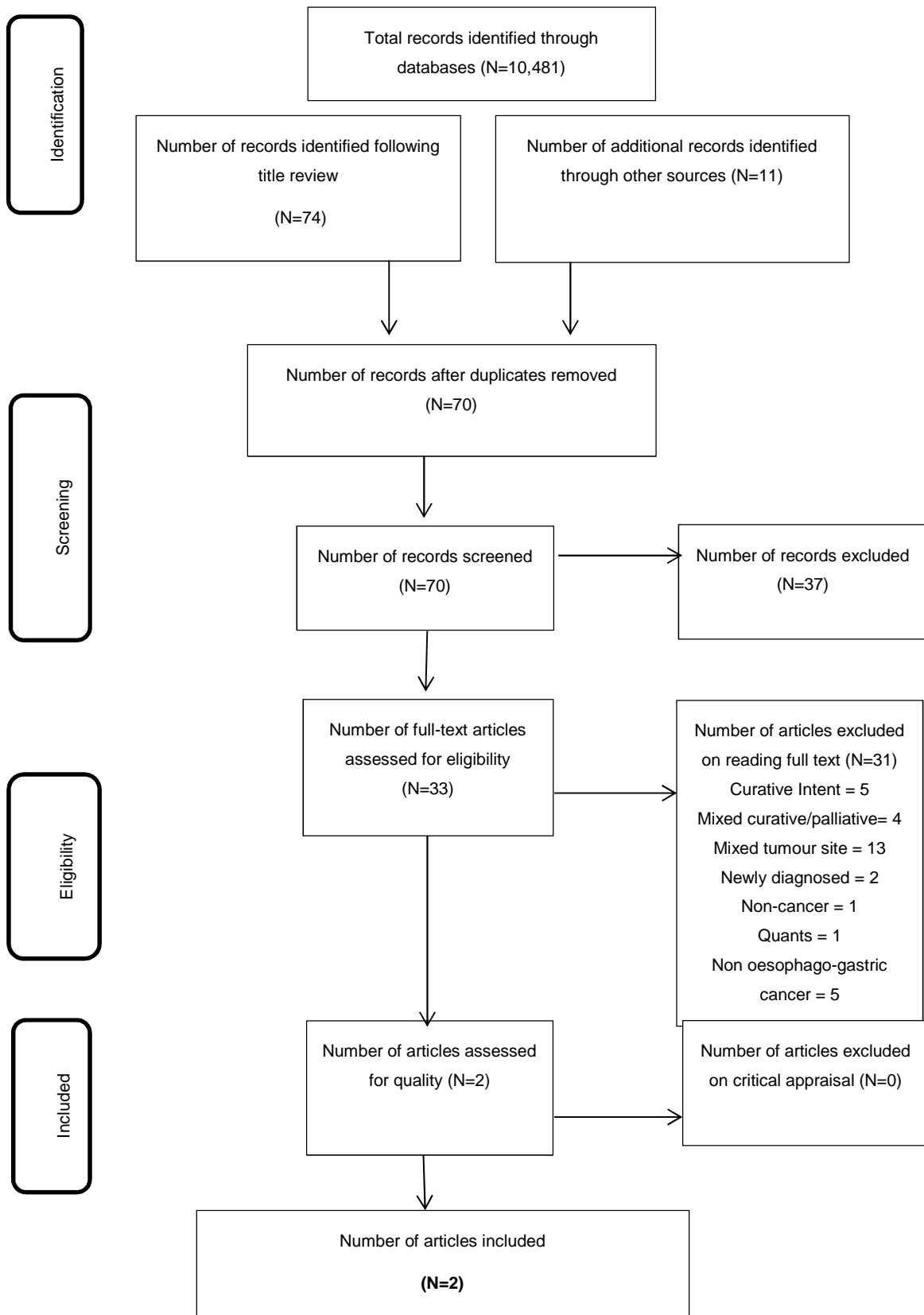
### **Data synthesis**

Qualitative research findings were pooled using JBI-QARI. This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that could be used as a basis for evidence-based practice.

To assist users of qualitative systematic reviews to establish assurance in the findings of this review, the synthesised findings were assessed for confidence using the ConQual approach<sup>15</sup> where findings were ranked according to dependability, credibility and given a ConQual score. All qualitative studies start with a ranking of 'high' on a scale of High, Moderate, Low to Very Low and are then downgraded based on their dependability and credibility.<sup>15</sup> The ConQual tool was developed to enable those accessing the evidence to establish confidence in the findings to make recommendations for practice and assist in decision making. Findings from qualitative reviews frequently inform practice, guidelines and policy recommendations, complementing quantitative evidence and reviews.<sup>15</sup>

### **Results**

Following a comprehensive and systematic literature search of the identified databases, 10,481 results were found and which were then filtered by year. Additional records were identified through a cited reference search. Titles were then reviewed and 85 records were found. An example of search results from AMED can be found in appendix IV. With duplicates removed a total of 70 records were screened by reviewing their title and abstract to assess for suitability against the search strategy and inclusion criteria. 37 records were excluded, the majority being quantitative research, general palliative care, and non-specific tumour site cancer research or opinion pieces. 33 articles were obtained for full review and 31 were excluded with reasons detailed in appendix V. In order to clarify the patient population in three studies<sup>16,17,18</sup> the authors were contacted. Subsequently two studies were assessed for methodological quality using JBI critical appraisal tool (appendix II) and presented in table 3. Figure 1 presents details of the search process and results.



**Figure 1: search results<sup>19</sup>**

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic

Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097.

**Table 3 – Results for the final critical appraisal of studies included**

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Missel and Birkelund. <sup>20</sup>	Y	Y	Y	Y	Y	N	U	Y	Y	Y	8.5
Watt and Whyte. <sup>21</sup>	U	U	U	U	U	N	U	U	Y	N	4.5

### Description of studies

This review included two publications, both of which explored patients' experiences of their cancer.<sup>20,21</sup> Participants in these studies were not specifically asked about their perceptions or experiences of care or how care should be delivered. Participants in Missel and Birkelund's study<sup>20</sup> had incurable EG cancer but it was not outlined how they were recruited to the study. Participants were asked to talk broadly about their lives using a narrative approach. The Watt and Whyte study<sup>21</sup> asked EG cancer patients undergoing palliation of their experience of dysphagia and how it affected their quality of life. This mixed methods study comprised a concurrent quantitative and qualitative study design using quality of life questionnaires and semi-structured interviews to uncover the phenomena of interest.

The papers were published in 2003 and 2011 in journals the European Journal of Cancer Care and European Journal of Oncology Nursing respectively. The studies were carried out in Northern European Countries; Denmark<sup>20</sup> and Scotland.<sup>21</sup>

These countries have differing structures of health service provision and delivery of palliative care services within the acute and community sector.

One of the studies was carried out in non-English language<sup>20</sup> but the study findings were reported and published in English.

The paper by Missel and Birkelund<sup>20</sup> adopted a qualitative approach employing a phenomenological hermeneutical epistemology seeking to uncover information-rich perceptions and experiences of the phenomena of interest employing narrative interviews. The mixed methods study by Watt and Whyte<sup>21</sup> adopted a phenomenological interpretative approach to the interviews which were completed

after the questionnaires on quality of life. The quantitative findings from the questionnaires were not considered as part of this review.

Participants in both papers were purposively sampled by their experience of being diagnosed with incurable EG cancer<sup>20, 21</sup> accessing acute in-patient and outpatient services. It was difficult to establish from the studies if any of the participants were receiving in-patient care whilst taking part in the studies or what services or support they were receiving during the studies.

Approaches to data analysis varied across the studies and included the Ricoeur narrative theory with threefold mimesis<sup>20</sup> and Colaizzi analysis.<sup>21</sup> The Ricoeur analysis is an analytical approach that holds that patient stories are not empirical data but about reality, bringing real understanding and intersubjective knowledge<sup>20</sup>. Colaizzi analysis involves examining each individual phrase and formulating thematic sentences which are then arranged into themes.

No studies exploring staff experiences and perceptions of palliative EG cancers were found.

Characteristics of the included studies can be found in appendix VI.

### **Methodological quality**

. The two papers<sup>20, 21</sup> selected were included in the final synthesis, regardless of the results of the critical appraisal.<sup>15</sup> One paper<sup>20</sup> scored highly in terms of methodological quality with clear articulation of epistemology, methodology and methods employed but the paper by Watt and Whyte<sup>21</sup> scored poorly in this assessment. This was in part due to the presentation of the qualitative evidence as part of a mixed methods study and lack of evidence about the theoretical underpinning for how these results were merged. The study was included in the synthesised findings as it shed important insight into the impact that dysphagia has on quality of life, one of the most common presenting symptoms during disease presentation and progression.<sup>22</sup>

Synthesised findings were subjected to appraisal using the ConQual approach described in Munn, Porritt, Lockwood et al.<sup>15</sup> see table 1. This approach seeks to assist users of qualitative systematic reviews to establish confidence in review findings to facilitate clinical decision making. The dependability and credibility of the synthesised finding was downgraded by 2 levels, due to the weak methodological quality of the Watt and Whyte paper<sup>21</sup> and this resulted in an overall ConQual score of 'low' for the review.

### **Findings of the review**

There were 46 findings from the two papers included in the review and these were aggregated into four categories. Findings can be found in appendix VII. The four categories were then synthesised into one overall finding which is detailed in figure 2. Only findings that were rated unequivocal or credible were used to develop the metasynthesis. In the paper by Watt and Whyte<sup>21</sup> only findings from the qualitative semi-structured interviews were included.



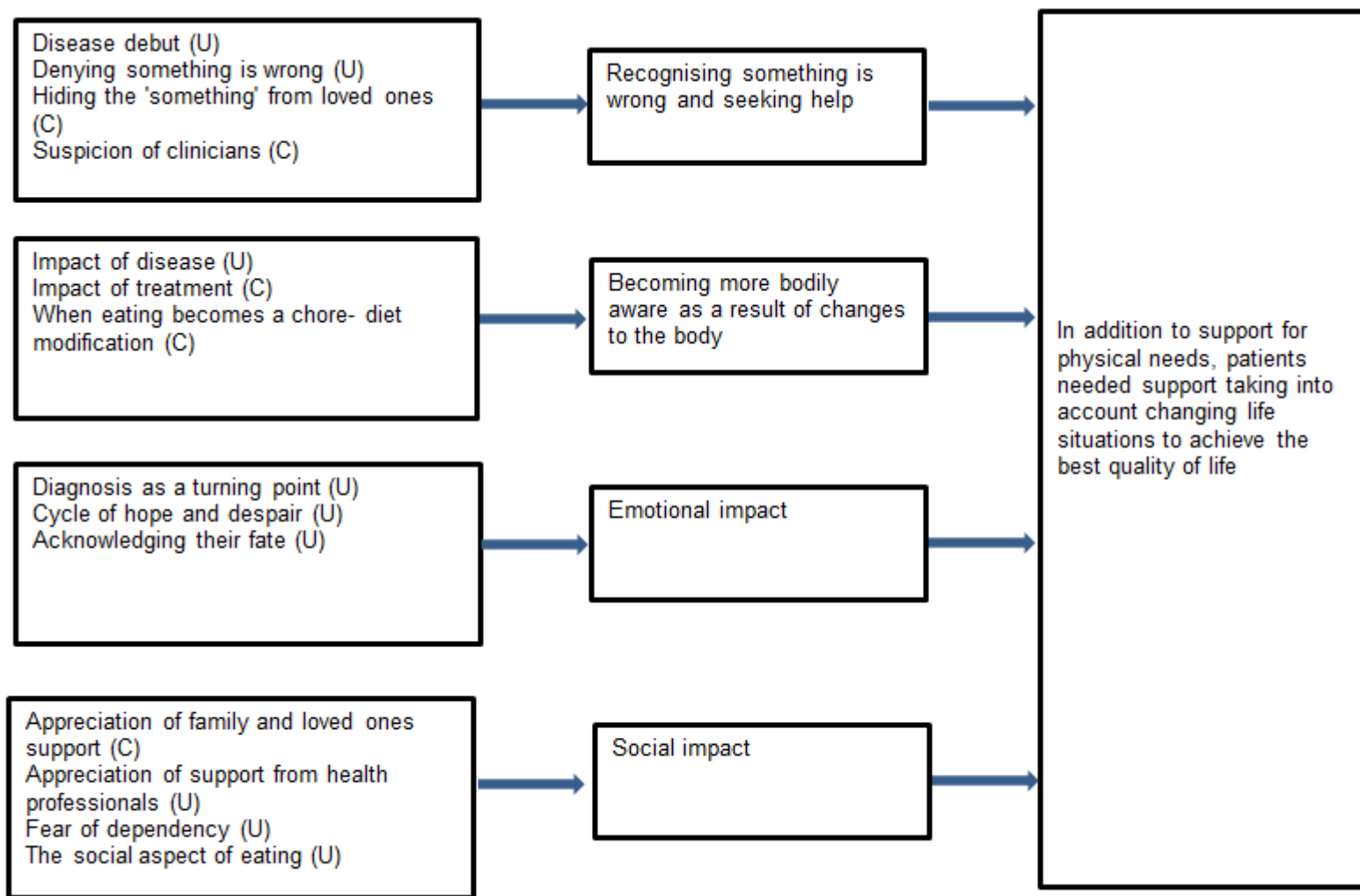


Figure 2: Results of metasynthesis of qualitative research findings

**Overall Synthesised Finding: In addition to support for physical needs, patients needed support taking into account changing life situations to achieve the best quality of life**

Participants expressed the need for support from health professionals that addressed their physical needs relating to symptom and disease management but that also took into account their changing life situation and likely terminal diagnosis. The synthesised findings shed light on how this phenomena of addressing physical symptoms and “the life situation” was present throughout the cancer journey; from presenting symptoms, to diagnosis and during palliative care provision. Participants valued time to talk about their experience which was often revisited on numerous occasions as their condition progressed, fluctuating between states of hope for the future and despair at their situation. These experiences were highly individualised and not linear, where participants experienced times when they valued support from staff and significant others, but found dependency on others challenging. In addition their journey towards death varied from despair and shock, to hope and accepting their fate, and making the most of their complex situation. This opportunity to revisit their story and life experiences allowed a period of self-reflection.

**Category 1 – Recognising something is wrong and seeking help**

Participants reported a gradual awareness that something was not as it should be, which was frequently reported as pain and/or difficulty with swallowing. In some instances, participants described convincing themselves that these symptoms were not indicative of something serious and continued with daily life: *“I persuaded myself that it wasn’t serious and just got on with my life.”*<sup>20(p298)</sup> and when they eventually sought out medical help ensuring that their concerns were taken seriously was viewed as a key moment in their disease trajectory and overall patient experience. Some found that their symptoms were taken seriously and addressed quickly by health professionals but others found that their complaints were not taken seriously. This not only delayed diagnosis and treatment options but heightened participants’ anxiety and concerns.

While participants may have hid the extent of their condition from their families and significant others, this relationship may have been the trigger for them to actively seek help when their difficulties started to impact on relationships and social situations: *“No he doesn’t know about the gullet problem because they have their dinner separate. I maybe have mine when I feel like something. I am not at the table with them.”*<sup>21(p190)</sup>

**Category 2 - Becoming more bodily aware as a result of changes to the body**

As a result of the cancer and treatment, participants became more aware of their body. Changes to physical appearance was equally as powerful as symptoms associated with their cancer diagnosis and the sight and experience of living in a “decaying” body meant that participants became more

aware of their body and its significance on their health. Participants reported feeling shocked at changes such as weight loss, choking, coughing and subsequent fatigue and tiredness: *"I could hardly recognise my body after the chemotherapy. It was so different. I was really afraid of myself - my body is decaying and I can't do anything about it."*<sup>20(p298)</sup> Bodily functions, which were once automatic and taken for granted, were given greater consideration as they declined. As a result of dysphagia, eating became an activity about which they became more consciously aware as difficulty with swallowing progressed. Rather than being a pleasure, eating became a chore and something which many expressed as a fearful experience, sometimes avoiding totally with the sensation of hunger being frequently suppressed: *"As first I was hungry but now I am getting that I don't care if I eat. It's not the same at all you don't enjoy any food, you really don't enjoy food."*<sup>21(p188)</sup> Participants described having to force themselves to eat and eating therefore became a frightening and fearful experience. Dietary modifications resulted in limitation of choice and pleasure in eating both within the home and hospital setting.

Pain associated with swallowing was a significant issue in the practicalities of eating and was said to result in anxiety and fear in something that was once found pleasurable.

Being aware of changes to their body made participants more cognisant of the disease process and the impact that their terminal diagnosis had on their life. This led to participants commencing a period of self-reflection about their life and increased attention on which aspects they wished to focus their energies during their remaining life: *"I try to resign myself to the fact that I am going to die and that now the treatment will make my last days' worth living."*<sup>20(p298)</sup>

### **Category 3 – Emotional Impact**

The emotional cost of the diagnosis had a substantial impact on participants' quality and views of life, one which participants described as a turning point in their lives. Whilst having to deal with the physical ramifications of the disease and symptom management, the emotional effects were significant amongst participants in the studies.

The diagnosis often came as a shock or confirmation that something had been wrong and participants reported needing time, space and support to accept this at their own pace: *"I felt that my life was at an end, why me? Why now?"*<sup>20(p298)</sup> Feelings fluctuated between fear and acceptance, hope and hopelessness and during this time participants valued open communication and support strategies from health professionals. This cycle of hope and hopelessness was commonly reported and helped participants in accepting their death and making the most of their life.

Even though participants knew that they were close to death they still made positive evaluations of their situation and strived to make the most of their remaining life and acknowledged death: *"The cancer was back, and it had spread to my liver... I feel that I am trying to take things in my stride, but I must say that both my wife and I were very shocked. We had always kept our hopes up that they*

*could at least keep the cancer at bay, so it was a bit of a let-down for us. I still try to focus on the good years I have had and meet my fate but it is difficult sometimes.*"<sup>20(p298)</sup>

#### **Category 4 – Social Impact**

Participants reported that a diagnosis of palliative EG cancer had significant impact on their social situation and interactions with significant others and health professionals.

Their social lives were adversely affected especially in regards to eating; what was once a pleasurable social interaction with family and friends became problematic. Participants reported fear associated with eating and at times avoided eating in public or around others due to pain, embarrassment, lack of appetite, reduced food choices and/or choking. This was reported to lead to social isolation and avoidance of eating which also adversely affected other physical factors associated with nutritional intake such as, weight, energy levels and fatigue: *"I know I need to eat and get nourishment I can feel the energy sapping away. I push myself to do it because I know if I don't eat I'll not be here in a month. I'll just die of starvation.*"<sup>21(p189)</sup>

Participants placed value on support from their families and friends and the opportunity to repeatedly talk about their experiences, hopes and fears: *"It has meant more to me than the professional care from nurses and doctors.*"<sup>20(p299)</sup> However some participants described being reluctant to burden their family with these challenging emotions or had close relationships which allowed them to express and explore their emotions and experiences: *"I don't see a lot of them (family) which I could do, I could be away on holiday with them and I don't visit the same because I am not feeling right. I don't want to be embarrassed trying to eat...I do miss the company.*"<sup>21(p190-191)</sup>

Participants reported that despite valuing support, they did not wish to be a burden or dependent on their relatives and friends.

Relationships with health professionals were also valued once a palliative diagnosis had been given where open, honest and clear communication was seen as vital and founded the basis of the relationship. The ability to talk over and over their experiences to help them come to terms and frame their life situation was important.

#### **Discussion**

The overall objective of this systematic review was to synthesize the best available evidence on the experiences and perceptions of patients and health professionals with regard to the care of people diagnosed with palliative EG cancer. To focus on their experiences of delivering and receiving care, the most appropriate and acceptable ways this should be delivered and beliefs on what constitutes the best quality of life.

### **Seeking help and diagnosis**

Patients' initial experiences of seeking help from health professionals when their symptoms became troublesome were viewed as key milestones in their lives. The synthesised findings showed that some patients' symptoms and concerns were not taken seriously by doctors and that this had a significant impact on their experience and anxiety levels. Experiences of misdiagnosis and delays in diagnosis were not uncommon in EG cancer<sup>25</sup> with symptoms often being mistaken for indigestion.<sup>26</sup> Due to the fast paced nature of EG cancer, many patients do not present until their disease has progressed, leading to low survival rates at 5 years<sup>5</sup>. Ensuring health professionals have knowledge of the early symptoms and take patients concerns seriously would not only improve clinical outcomes and survival rates, but also improve patient experience. Andreassen, Randers, Naslund et al.<sup>24</sup> found that a delay in diagnosis was also associated with negative feelings from patients and family members, recommending that health professionals must strive to improve the content and quality of their interactions.

A diagnosis of palliative EG cancer was described as an existential turning point and this finding has been supported in other gastrointestinal cancer studies.<sup>24,25,40</sup> Öhlen, Wallengren Gustafsson and Friberg<sup>18</sup> found that patients with advanced gastrointestinal cancer spoke of their need for knowledge and understanding to help them make sense of everyday life and palliative treatment. Through personal reflection and evaluation and consulting with health professionals, patients were able to make sense of their end of life experience. In coming to terms with their life situation patients described a cycle of hope and hopelessness, fear and optimism.<sup>20</sup> Other studies on experiences of gastrointestinal cancer patients, with and without palliative needs, have also described these emotions<sup>17, 25, 36, 38, 40</sup> which were seen as a vital step in helping patients to make sense of the uncertainty about their future and diagnosis. The synthesised findings suggest that patients believe that care should be delivered which enables these interactions to occur, having time, support and open honest discussions with health professionals in order for them to make sense of their diagnosis and future.

Parallels can be drawn with the systematic review by Andreassen et al.<sup>14</sup> who found that healthcare professionals focussed on treatment and symptoms, failing to recognise emotional and existential concerns and suggested that healthcare professionals should seek to initiate these conversations in order to fulfil patient and carer needs.

### **Supporting emotional and social needs**

Lidén, Öhlen, Hyden et al<sup>16</sup> identified three interactional frameworks in palliative cancer care communication that shaped conversations between health practitioners, patients and carers. Adopting a person-to-person framework, rather than patient-professional framework, allowed patients to explore and share their personal experience and interpretations of illness and prognosis. Lidén et al<sup>16</sup>

warn that health professionals face an ethical challenge in exploring these situations as not all patients prefer a narrative approach to their care, some may prefer a more formal, practitioner led interaction model. Knowledge of communication style, methods and delivery can be seen as a key component in ensuring that individualised and high quality care is delivered.

Much of the care delivered to palliative care cancer patients is delivered by social and health care staff who may not have received specialist training in communication strategies and approaches<sup>11</sup> so opportunities for these discussions may be missed. Wider training is therefore needed to adequately equip the workforce to recognise the social and emotional impact of a terminal diagnosis. The review did not find any studies which explored experiences, perceptions or perceived training needs for hospital or community based staff working with palliative EG cancer patients. Given that this patient group has complex and fluctuating clinical needs, frequently requiring specialist input from nurses, dieticians, speech and language therapists and medical staff<sup>9</sup>, further research is recommended to explore how staff deliver care.

Palliative care frameworks recommend that care is delivered across multiple settings which may include hospital, specialist hospices, care homes and the patients' home.<sup>11</sup> This review was unable to uncover where patients or carers believed these interactions should occur and how the environment influenced the nature of quality of interactions. Thon Aamodt, Lie and Hellesø<sup>23</sup> explored ward based nurses' perspectives of palliative care needs in advanced gastrointestinal cancer patients in Norway and found that there was a lack of knowledge about available services and uncertainty about the clinical skills of nurses in the community. They primarily spoke of addressing physical symptoms of pain, which were also found to be vital in this review in achieving the best quality of life.<sup>20, 21</sup>

### **Dysphagia – more than a physical problem**

Dysphagia in curative and palliative EG cancer has been found to have a significant impact on quality of life.<sup>21</sup> This review found that patients became more aware of their body and specifically swallowing as a result of their illness and that eating became a chore. The management of dysphagia and the physical experience of dysphagia in EG cancer have been extensively studied<sup>22, 25, 31, 32, 35, 38, 39</sup> and it was not the purpose of this study to specifically investigate the impact and management of dysphagia. However the study by Watt and Whyte<sup>21</sup> into the experience and impact of dysphagia on palliative EG cancer patients, included in this review, provided interesting insights into the impact of dysphagia on emotional and social well-being. Fear of eating, choking and food avoidance was identified as significant issues by patients who had social and emotional impact. Eating, whilst a biological necessity also has strong social and cultural implications and the presence of dysphagia means that patients may not engage in eating out or eating with other family members, creating a sense of social isolation. Participants in the study by McCorry, Dempster, Clarke et al.<sup>40</sup> also felt embarrassed and nervous about eating out, with some describing a social stigma after curative esophagectomy. To

ensure that these issues are explored, a multi-professional approach to swallowing and diet is recommended and indeed is echoed in clinical guidelines and service frameworks.<sup>11</sup>

### **Family and carer perspective**

The original review question did not seek out family members perspectives and experiences, but patients placed high value on support from family members, carers or significant others, both in terms of physical and emotional support. No studies were identified that specifically explored carer/family perceptions of how services were delivered to palliative EG patients. Previous studies into living with incurable cancer and coping with newly diagnosed EG cancer have explored caregiver roles and supportive care needs.<sup>24,27,30,40</sup> Shaw, Harrison, Young et al<sup>47</sup> found that family caregivers of newly diagnosed upper gastrointestinal cancer patients experienced significant distress over the changed dynamics of their relationship with their relative, citing the lack of information and challenges in navigating healthcare systems as significant stressful factors.

### **Limitations**

The search strategy excluded patients who were treated with curative intent but a number of studies were identified that examined patient and carer experiences of surgery or living with esophageal cancer.<sup>25,27,37,38,41,42,47,49</sup> Given the poor survival rates associated with EG cancer, some of the participants in these studies were in receipt of palliative care but findings were unable to be extracted as it was unclear which phase of cancer management they were receiving.

The two studies included in the review were from European countries and may not be representative of other health and care contexts. Meta-synthesising the findings of the two papers proved challenging as they both sought to uncover different phenomena, as reflected by their research questions. The study by Missel and Birkelund<sup>20</sup> explored the life world of patients living with incurable esophageal cancer, whereas Watt and Whyte<sup>21</sup> focused on the specific symptom of dysphagia and how this affected quality of life.

The majority of the papers shortlisted for full review (n=32), although having interesting and potentially pertinent clinical findings and implications had to be excluded for a number of reasons. Many of the studies included participants with mixed tumour sites, including colorectal, lung, liver and gastric or head and neck and the inclusion criteria clearly stated that participants were to be diagnosed with EG tumours (i.e. a tumour at the distal oesophagus or gastro-esophageal junction). The findings of these studies therefore had to be excluded as the team were unable to ascertain which tumour site the findings related to. Although lessons could have been learnt from patient and staff experiences and perceptions of care, the disease progression and symptoms of EG cancer were deemed to be different in progression.

The review sought to identify primary research and therefore did not explore textual or expert opinion which may have shed further light on how services are currently designed and delivered or how clinicians, patients and carers believed they should be designed. A paper by Viklund and Lagergren<sup>52</sup> presented their vision of a patient pathway for esophageal cancer which included how patients with palliative care needs were supported but this was excluded as it was not primary research.

Patient and staff experiences of supportive care for non-curative EG cancer is a challenging phenomenon to isolate given that the cancer journey is rarely linear and it may have been useful to explore the transition from curative to palliative care in order to inform future research and recommendations about how services are designed and provided.

The review question focussed on identifying patient and staff experiences and did not include carer or family experiences but no evidence was unearthed which shed light on this phenomena.

## **Conclusion**

The synthesised findings show that patients value services and support that address their complex, fluctuating and highly individualised needs taking into account physical, emotional and social issues throughout their cancer journey. NICE<sup>11</sup>, the NHS Cancer Plan<sup>9</sup> and Improving Supportive and Palliative Care for Adults with Cancer<sup>10</sup> all highlight the importance of offering care and support which takes into account more than physical symptoms, which should also include emotional, spiritual and social support.

## **Implications for practice**

Drawing from the synthesized findings of the review, several recommendations for clinical practice have been made. These findings support existing recommendations made by NICE<sup>11</sup> and have been graded according to the JBI grades of recommendation (see appendix VIII).

- Patients want their concerns and symptoms to be taken seriously by medical staff, especially during initial presentation. Health practitioners need to be aware of the early symptoms of EG cancer and understand that early detection can lead to improved survival rates. Knowing that their concerns are being listened to and acted upon can reduce levels of anxiety in some patients (Grade B).
- Supportive care should take into account the holistic needs of patients including the physical, emotional and social impact of the disease and not just focus on objective outcomes (Grade B).



- Patients value the opportunity to continually talk about their experience in order to make sense of their diagnosis and future. Health professionals need to have the necessary skills in order to recognise this need and support patients and carers throughout the trajectory of their illness (Grade B).
- Patients experience cycles of hope and despair which helps them acknowledge their diagnosis and helps them plan for the future. This is a highly individualised process and health professionals need to recognise these emotions and support patients to explore what constitutes a good quality of life for their patient (Grade B).
- Patients believe that care should be delivered using open, honest and clear communication in order to manage expectations, reduce anxiety and maintain a sense of independence (Grade B),
- The impact of dysphagia and difficulties associated with eating should be considered from a physical (swallowing, choking, pain, nutritional requirements) and from an emotional and social perspective. Health professionals should investigate and support possible anxiety and fear associated with eating and the social isolation that can result when eating becomes a chore (Grade B).
- Patients with dysphagia have specific nutritional requirements and these should be addressed (Grade B).
- Patients appreciate the support of family and loved ones. They may want them involved in planning care but clinicians should also recognise that patients may hide the extent of their problems from family members (Grade B
- ).

### **Implications for research**

Further high quality qualitative research needs to be carried out to explore experiences and perceptions of care from the patient, and staff perspective in palliative EG cancer. Specific research questions should include how and where the care is delivered, what models of care should be offered, how these influence quality of life and what quality of life looks like for participants. Experiences and perceptions across the multi-professional team should be considered in both hospital and community settings in order for the complete patient pathway to be fully explored.

### **Conflict of interest**

The team has no conflicts of interest

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## Appendix I: Full Search strategy

For use with following databases: OVID / AMED / BNI / EMBASE / MEDLINE / PsycInfo

### 1 Population:

("Oesophago-gastric cancer\*" or "Oesophago-gastric tumour\*" or "Oesophago-gastric neoplasm\*" or "Oesophageal cancer\*" or "Oesophageal tumour\*" or "Oesophageal neoplasm\*" or "Gastro-oesophageal junction cancer\*" or "Gastro-oesophageal junction tumour\*" or "Gastro-oesophageal junction neoplasm\*" or "Gastric cancer\*" or "Gastric tumour\*" or "Gastric neoplasm\*" or "Esophago-gastric cancer\*" or "Esophago-gastric tumour\*" or "Esophago-gastric neoplasm\*" or "Esophageal cancer\*" or "Esophageal tumour\*" or "Esophageal neoplasm\*" or "Gastro-esophageal junction cancer\*" or "Gastro-esophageal junction tumour\*" or "Gastro-esophageal junction neoplasm\*" or "Stomach cancer\*" or "Stomach tumour\*" or "Stomach neoplasm\*" or "Gastrointestinal cancer\*" or "Gastrointestinal tumour\*" or "Gastrointestinal neoplasm\*") .mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

"Oesophago-gastric cancer\*" or "Oesophago-gastric tumour\*" or "Oesophago-gastric neoplasm\*" or "Oesophageal cancer\*" or "Oesophageal tumour\*" or "Oesophageal neoplasm\*" or "Gastro-oesophageal junction cancer\*" or "Gastro-oesophageal junction tumour\*" or "Gastro-oesophageal junction neoplasm\*" or "Gastric cancer\*" or "Gastric tumour\*" or "Gastric neoplasm\*" or "Esophago-gastric cancer\*" or "Esophago-gastric tumour\*" or "Esophago-gastric neoplasm\*" or "Esophageal cancer\*" or "Esophageal tumour\*" or "Esophageal neoplasm\*" or "Gastro-esophageal junction cancer\*" or "Gastro-esophageal junction tumour\*" or "Gastro-esophageal junction neoplasm\*" or "Stomach cancer\*" or "Stomach tumour\*" or "Stomach neoplasm\*" or "Gastrointestinal cancer\*" or "Gastrointestinal tumour\*" or "Gastrointestinal neoplasm\*"

And

### 2 Intervention and Processes search combined

("Palliative care" or "Phase of palliation" or "Palliative phase\*" or "Palliative approach#" or "Palliative treatment intent\*" or "Palliative treat\*" or "Palliative therap#" or "Palliative intervention\*" or "Symptom palliation\*" or "Palliative chemotherapy" or "Palliative radiotherapy" or "Palliative surgery" or "Palliative endoscopy" or "Palliative stent#" or "Supportive palliative care" or "supportive care" or "No active treatment\*" or "Non curative treatment\*" or "Best supportive care" or "Ease burdensome symptom\*" or "Hospice" or "Patient centred care" or "Patient centered care" or "Survivorship" or "Comfort care" or "Terminal care" or "Holistic care" or "End-of-life care" or "End of life care" or "Liverpool care pathway" or "Gold standard framework" or "Model\* of care" or "Model\* of practice" or "Mode\* of delivery" or "Shared decision making" or "Decision making" or "Patient management" or "Integrated care

pathway\*" or "Integrated care model\*" or "Clinical pathway\*" or "Care pathway\*" or "Improved support" or "Cancer journey" or "Agreed protocol\*" or "Aftercare" or "Self management" or "Self-management" or "Day care" or "Acute care" or "Patient care" or "Primary care" or "Service delivery" or "Service model\*" or "Organisation of care" or "Organization of care").mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

**Amendment for use with CINAHL database:**

"Palliative care" or "Phase of palliation" or "Palliative phase\*" or "Palliative approach" or "Palliative approaches" or "Palliative treatment intent" or "Palliative treatment\*" or "Palliative treatments" or "Palliative therapy" or "Palliative therapies" or "Palliative intervention" or "Palliative interventions" or "Symptom palliation" or "Palliative chemotherapy" or "Palliative radiotherapy" or "Palliative surgery" or "Palliative endoscopy" or "Palliative stent" or "Palliative stents" or "Supportive palliative care" or "supportive care" or "No active treatment" or "Non curative treatment" or "Best supportive care" or "Ease burdensome symptoms"



**Appendix II: Appraisal instruments**

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year ..... Record Number .....

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:  Include  Exclude  Seek further info.

Comments (Including reason for exclusion)

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**Appendix III: Data extraction instruments**

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year .....

Journal ..... Record Number .....

**Study Description**

Methodology  
.....  
.....

Method  
.....  
.....

Phenomena of interest  
.....  
.....

Setting  
.....  
.....

Geographical  
.....  
.....

Cultural  
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Participants  
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Data analysis  
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Authors Conclusions  
.....  
.....

Comments  
.....  
.....

Complete

Yes

No

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete

Yes

No

**Appendix IV: Example of search results from AMED**

Number	Searches	Results	Type
1	("Oesophago-gastric cancer*" or "Oesophago-gastric tumour*" or "Oesophago-gastric neoplasm*" or "Oesophageal cancer*" or "Oesophageal tumour*" or "Oesophageal neoplasm*" or "Gastro- oesophageal junction cancer*" or "Gastro-oesophageal junction tumour*" or "Gastro-oesophageal junction neoplasm*" or "Gastric cancer*" or "Gastric tumour*" or "Gastric neoplasm*" or "Esophago-gastric cancer*" or "Esophago-gastric tumour*" or "Esophago-gastric neoplasm*" or "Esophageal cancer*" or "Esophageal tumour*" or "Esophageal neoplasm*" or "Gastro-esophageal junction cancer*" or "Gastro-esophageal junction tumour*" or "Gastro-esophageal junction neoplasm*" or "Stomach cancer*" or "Stomach tumour*" or "Stomach neoplasm*" or "Gastrointestinal cancer*" or "Gastrointestinal tumour*" or "Gastrointestinal neoplasm*").mp. [mp=abstract, heading words, title]	518	Advanced
2	("Palliative care" or "Phase of palliation" or "Palliative phase*" or "Palliative approach#" or "Palliative treatment intent*" or "Palliative treat*" or "Palliative therap#" or "Palliative intervention*" or "Symptom palliation*" or "Palliative chemotherapy" or "Palliative radiotherapy" or "Palliative	26368	Advanced

	<p>surgery" or "Palliative endoscopy" or "Palliative stent#" or "Supportive palliative care" or "supportive care" or "No active treatment*" or "Non curative treatment*" or "Best supportive care" or "Ease burdensome symptom*" or "Hospice" or "Patient centred care" or "Patient centered care" or "Survivorship" or "Comfort care" or "Terminal care" or "Holistic care" or "End-of-life care" or "End of life care" or "Liverpool care pathway" or "Gold standard framework" or "Model* of care" or "Model* of practice" or "Mode* of delivery" or "Shared decision making" or "Decision making" or "Patient management" or "Integrated care pathway*" or "Integrated care model*" or "Clinical pathway*" or "Care pathway*" or "Improved support" or "Cancer journey" or "Agreed protocol*" or "Aftercare" or "Self management" or "Self-management" or "Day care" or "Acute care" or "Patient care" or "Primary care" or "Service delivery" or "Service model*" or "Organisation of care" or "Organization of care").mp. [mp=abstract, heading words, title]</p>		
3	1 and 2	296	Advanced
4	limit 3 to yr="2000 – 2015"	140	Advanced

**Appendix V: Excluded studies**

	<b>Study</b>	<b>Reason for exclusion</b>
1	Aamodt, Lie, Hellesø (2013) <sup>22</sup>	Explored nurse experience on general gastroenterology ward, mixed patient population with palliative needs
2	Andreassen, Randers, Näslund et al. (2005) <sup>23</sup>	Recruited family members of participants with oesophageal cancer - unclear if curative or palliative intent
3	Andreassen, Randers, Näslund et al. (2006) <sup>24</sup>	Mixed population of curative and palliative intent
4	Andreassen, Randers, Näslund et al (2007) <sup>26</sup>	Newly diagnosed cancer, unclear if curative or palliative
5	Checton, Greene, Magsamne-Conrad et al. (2012) <sup>27</sup>	Cancer excluded from study
6	Chen (2014) <sup>28</sup>	Mixed study population of breast, head and neck, oesophageal
7	Chen, Chen, Lotus Shyu et al (2007) <sup>29</sup>	Mixed tumour site population
8	Ellis, Brearley, Craven, Molassiotis (2013) <sup>30</sup>	Data excerpts all from gastric and colorectal patients
9	Garland, Lounsberry, Pellertier et al (2011) <sup>31</sup>	Stomach cancer case study
10	Friberg, Öhlén (2007) <sup>32</sup>	Single case study of participant with colitis cancer
11	Henselmans, Jacobs, van Berge Henegouwen et al. (2012) <sup>33</sup>	Participants had undergone surgery with curative intent.
12	Jaromahum, Fowler (2010) <sup>34</sup>	Participants being treated with curative intent
13	Karlsson, Friberg, Wallengren et al. (2014) <sup>35</sup>	Primary tumour sites liver, colon and unknown
14	Lidén, Öhlén, Hydén et al (2010) <sup>15</sup>	Sample included various metastasised gastric tumours
15	Lim, Tadmor, Fujisawa et al (2014) <sup>36</sup>	Mixed tumour site participants included lung, oesophageal.
16	Malmström, Klefsgard, Johnansson et al.	Undergone surgery with curative intent and

	(2012) <sup>37</sup>	mixed population of oesophageal and gastric cancer. Those with disease relapse were excluded
17	Malmström, Ivarsson, Johansson et al (2013) <sup>38</sup>	Participants had undergone surgery with curative intent. Those with relapse of the disease were excluded
18	McCorry, Dempster, Clarek, Doyle (2009) <sup>39</sup>	Participants had undergone surgery with curative intent
19	Michael, O'Callaghan, Baird et al, (2014) <sup>40</sup>	Mixed tumour site of participants - lung, gastrointestinal
20	Nissim, Gagliese, Rodin (2009) <sup>41</sup>	Mixed tumour site of participants - colon, lung, pancreas
21	Nissim, Rennie, Fleming et al (2012) <sup>42</sup>	Mixed tumour site of participants - colon, lung, pancreas
22	Öhlén, Bengtsson, Skott et al. (2002) <sup>16</sup>	Mixed participant population of gastrointestinal cancer (not purely oesophageal)
23	Öhlén, Elofsson, Hydén et al. (2008) <sup>43</sup>	Participants mixed population of gastric cancers - including primary and metastasised
24	Öhlén, Wallengren Gustafsson, Friberg (2013) <sup>17</sup>	Primary tumour sites liver, colon
25	Olsson, Bergbom, Bosaeus (2002) <sup>44</sup>	Mixed population of curative and palliative intent
26	Olsson, Bergbom, Bosaeus (2002) <sup>45</sup>	Mixed population of curative and palliative intent
27	Shaw, Harrison, Young et al (2013) <sup>46</sup>	Participants had newly diagnosed malignancy and undergoing surgery for curative intent. Mixed population of gastric, liver, oesophagus and pancreas
28	Shin, Cho, Roter et al (2013) <sup>47</sup>	Quantitative survey
29	Uitdehaag, van der Velden, de Boer et al. (2012) <sup>48</sup>	Mixed participant population of head and neck and oesophageal cancer patients. Quantitative methodology
30	Verschuur, Steyerberg, Kuipers et al. (2006) <sup>49</sup>	Participants had undergone surgery with curative intent

31	Yi, Kahn (2004) <sup>50</sup>	Non-oesophageal cancer
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**Appendix VI: Characteristics of included studies**

Authors	Country	Clinical Setting	Phenomena of Interest	Methodology	Methods	Data Analysis	Participants	Study Aims	Conclusion
Missel and Birkelund (2011) <sup>19</sup>	Denmark	Outpatient	Exploring circumstances and phenomena that are significant to patients with incurable oesophageal cancer – experience of situation and how the disease affects them	Phenomenological hermeneutic interpretative approach	Narrative interview	Ricoeur model	5 patients with incurable oesophageal cancer aged between 43 and 76 years	Circumstances and phenomena that are of particular significance for participants	Patients find themselves in a complex life situation, in which they need more than an objective estimate and fulfilment of need from hospital services,
Watt and Whyte	Scotland	In receipt of	Experience of dysphagia in	Phenomenological approach to	Semi-structure	Colaizzi approach	6 selected for semi-	Describe experience of	Dysphagia is a

(2003) <sup>20</sup>		palliative care services	palliative oesophageal cancer patients	qualitative data (mixed methods study which also included a questionnaire on quality of life)	depth interview	structured interviews, 5 female, 1 male aged between 63 and 85 years	dysphagia in patient with oesophageal cancer	troublesome symptom affecting all aspects of quality of life
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**Appendix VII: Extracted findings**

Missel M, Birkelund R. Living with incurable oesophageal cancer. A phenomenological hermeneutical interpretation of patient stories. European Journal of Oncology Nursing. 2011;15(4):296-301.<sup>19</sup>

Findings	Illustration from publication (page number)	Evidence		
		Unequivocal (U)	Credible (C)	Unsupported (US)
Disease Debut	"I didn't feel much at the beginning, only a little difficulty swallowing and sometimes a burning sensation" (p.298) This theme relates to the first experience of symptoms for example, difficulty swallowing and pain. These symptoms indicated to the participant that something was not as it should be.		✓	

Denial	<p>"I persuaded myself that it wasn't serious and just got on with my life" (p. 298)</p> <p>The participants have had the symptoms for some time before they go to the doctor, but only when they are admitted to hospital do they feel as though they are ill.</p>		✓	
Seeking help	<p>In the stories, it appears that there is a particular social situation which incites the participants to seek help.</p> <p>"It all started one evening in May, when I was trying to take a tablet for my hay fever. I nearly choked and couldn't even drink any water. My husband and I went straight to the A&amp;E" (p.298)</p>		✓	
Suspicion	<p>Several of the participants felt that the doctor at the initial consultation did not take them seriously. This delayed the treatment but also made the participants feel insecure and worried</p> <p>"The doctor said that it was gastric acid and that I should just have some tablets. I tried to tell him that it had to be more than that, but he insisted that I try the tablets and see him again if I still had problems. I felt really anxious when I left the doctor" (p.298)</p>		✓	
Existential turning point	<p>The diagnosis made the participants aware of the seriousness of the situation causing an existential turning point</p> <p>"I felt that my life was at an end, why me? Why now?" (p.298)</p>		✓	

Despair	The participants experienced despair and hopelessness "I didn't care about anything- I had just about given up beforehand" (p.298)		✓	
Hope	This period of despair was followed by periods of hope "After being in very low spirits for some time, I started to hope that I could survive this terrible disease. It was lovely - I was going home for Christmas and even though I could not eat anything, I was convinced that I still had a good life to look forward to" (p.298)		✓	
The Body	The body suddenly started "communicating" with them in a more direct and threatening way than previously "I could hardly recognise my body after the chemotherapy. It was so different. I was really afraid of myself - my body is decaying and I can't do anything about it." (p.298)		✓	
Disease perception linked to side effects of treatment	"Sometimes I started vomiting before I started the infusion" (p.298)		✓	
Acknowledging death	Participants may be told that the disease has spread in spite of their fighting spirit and the strenuous treatment "I was told that the cancer that I had was incurable" (p.298)		✓	
Prospect of dying	Participants try to come to terms with their situation and the prospect of dying "I try to resign myself to the fact that I am going to die and that now the treatment will make my last days' worth living" (p.298)		✓	

<p>Significance of life phenomena</p>	<p>The ability to appreciate life in spite of serious illness was very typical for the participants. Their courage was expressed in an unflinching will to exercise or just keep going by having daily objectives</p> <p>"The cancer was back, and it had spread to my liver(...) I feel that I am trying to take things in my stride, but I must say that both my wife and I were very shocked. We had always kept our hopes up that they could at least keep the cancer at bay, so it was a bit of a let-down for us. I still try to focus on the good years I have had and meet my fate but it is difficult sometimes" (p.298)</p>		<p>✓</p>	
<p>Social relations</p>	<p>Participants greatly appreciated the support and help they had received from family and friends.</p> <p>"It meant more to me than the professional care from nurses and doctors" (p.299)</p>		<p>✓</p>	
<p>Social Contact</p>	<p>Stories made it clear just how much the social relations mean to the participants. Their need for togetherness and nearness and to repeatedly talk about their situation was a common feature.</p> <p>"The contact with my family and friends was very important and helped me not to lose faith. I needed to talk about it over and over again." (p.299)</p>		<p>✓</p>	
<p>Feeling independent</p>	<p>Participants were ready to take on as much responsibility for themselves as possible. Being dependent on others was not described as a positive experience.</p> <p>"I need help for so many things and I am not happy about it,</p>		<p>✓</p>	

	as it has always been important for me to be able to take care of myself" (p.299)			
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Watt E, Whyte F. The experience of dysphagia and its effect on the quality of life of patients with oesophageal cancer. *European Journal of Cancer Care*. 2003;12(2):183-93.<sup>20</sup>

Findings	Illustration from publication (page number)	Evidence		
		Unequivocal (U)	Credible (C)	Unsupported (US)
Recognizing dysphagia	Although dysphagia had been the presenting symptom in all the participants, no one in the group anticipated it could mean anything sinister (p.187)			✓
Seeking help	Despite not recognising the significance of dysphagia, all other participants visited their own doctor promptly after developing the symptom (p.187)			✓
Shock of diagnosis	When asked how they felt when given the diagnosis of cancer all the participants described feelings of shock or disbelief  "I was absolutely stunned, I remember lying in my bed, turning my face to the wall after (Consultant) told me and I		✓	

	just cried" (p.187)			
Not being taken seriously by doctors	When consulting their doctor two of the participants found that their complaint was not taken seriously. One elderly lady who lived alone felt disappointed in her doctor and this was a theme that recurred throughout the interview (p.187)			✓
Delay in diagnosis	In this study the main reason for delay in diagnosis was due to a failing by the health professionals attending two of the participants to recognise the importance of the symptom [dysphagia] (p.188)			✓
Feelings of lack of respect or disinterest by health professionals	The feelings of lack of respect and disinterest described by the two participants in this study in relation to their delay in diagnosis are similar to those described by patients with non-malignant oesophageal dysphagia in[another study] (p.188)			✓
Having to think before you eat	"go canny today, don't eat anything or just a bit of ice cream because you could get in a mess" (p.188)		✓	
Lack of enjoyment of eating	"As first I was hungry but now I am getting that I don't care if I eat. It's not the same at all you don't enjoy any food, you really don't enjoy food. The only thing I enjoy is maybe that wee cup-a-soup.... I maybe have two or three a day if I feel		✓	

	like it you know. Even mashed potatoes done in the lowest way with gravy, I feel them lying" (p.188)			
Increased time taken to eat meals	All of the participants reported that it took them longer than normal to eat meals. In some instances meals were protracted by as much as one hour or in one participant's case her methods of solving the problem was to consistently eat less (p.188)			✓
Painful swallowing	The severity of [this] was elicited at interview by two patients "I just took a fork-full, and whether it expanded in me there (pointing to oesophageal area) I don't know but I was holding onto the work surface and was pressing against my washing machine. I couldn't even talk. I was drinking water and I was in agony for an hour before all that cleared. That was one terrible night. That was the worst night I ever had, it was then I just watched what I was eating" (p.188)		✓	
Choking when eating	During interview all participants said they had choked at some point during their illness and were concerned about this (p.188)			✓
Difficulties clearing phlegm and mucous	Problems with phlegm or mucous were described at interview by four participants. "It takes 3-4 h, that is a fact, before I pull myself together and then I begin to realise there are other things happening which are bad. Very, very, very bad. I am actually		✓	



	frightened to go to bed. I am frightened to go to bed because you feel you are going to die...I know I could go to sleep at any point of the day, but I am scared" (p.188			
Weight loss	One participant indicated that she was not worried about her weight being too low at present but said at interview she was concerned if her swallowing did not improve she would lose more weight (p.189)			✓
Lack of energy	At interview ...three participants described concerns about weakness or lack of energy. One man said he hadn't believed it possible to feel so weak, he attributed this to lack of food although in this case his cancer was advanced and it is impossible to say what degree his problems with dysphagia contributed to his weakness (p.189)			✓
Shock at the bodily effects	One lady who had lost two stones in weight and was not six and a half stones, described her feelings "Well to be honest it just makes me not want to look at my own body. I hate it..."that's me blooming skeleton" but no it definitely takes your life away there is no getting away from it. I just feel as though I am standing at a bus stop waiting for a funeral procession to come up and that's it" (p.189)		✓	
Emotional feelings about eating	"I felt like crying. I felt like crying....I could smell it and thought On I could try that and knew in myself as soon as I tried it I wouldn't get it down I would be sick...the smell made me hungry and when I did get it I couldn't eat it at all. That was the worst thing about it. I couldn't eat and it made		✓	

	me that hungry I was starving I was" (p.189)			
The chore of eating	For some participants eating had become a "chore" and something they no longer associated with pleasure, one participant even said he found food "repulsive" (p.189)		✓	
Feelings of fear, anxiety and insecurity about food	"I felt like crying. I felt like crying....I could smell It and thought On I could try that and knew in myself as soon as I tried it I wouldn't get it down I would be sick...the smell made me hungry and when I did get it I couldn't eat it at all. That was the worst thing about it. I couldn't eat and it made me that hungry I was starving I was" (p.189)		✓	
The necessity of food for energy and survival	The patients in this study were aware of the importance of eating and the consequences lack of food could have in terms of both energy and survival "I know I need to eat and get nourishment I can feel the energy sapping away. I push myself f to do it because I know if I don't eat I'll not be here in a month. I'll just die of starvation" (p.189)		✓	
Meeting nutritional needs in hospital	Express their feelings that when in hospital their nutritional needs were not met "It was just too stodgy and solid, and by the time they got around to giving me some extra gravy or extra stuff I would be going home anyway...Well it was just solid food wasn't it" (p.190)		✓	
Low mood	Participants recounted feeling low and down hearted in relation to their problem		✓	

	"I'll face anything and I can stand pain but I am just not the same. I think it's getting on top of me I really do because I am fed up with not getting a decent but of food" (p.190)			
Sense of hopelessness	"waiting for a funeral procession" (p.190)		✓	
Sense of hope and positive outlook	"I think I have been quiet fortunate, when I think of the things o could have had like Alzheimer's" (p.190)		✓	
Impact on eating out as part of social life	One participant described the thought of going out for a meal like "putting her head in the lion's den" (p.190)		✓	
Hiding the extent of the problem from loved one's	Another lady had actually concealed the problem from her family, only her husband knowing despite the fact that her son also shared the same house "No he doesn't know about the gullet problem because they have their dinner separate. I maybe have mine when I feel like something. I am not at the table with them" (p.190)		✓	
Sense of isolation from family	The sense of isolation through the loss of the social role as a result of dysphagia is captured in this patient's description  "I don't see a lot of them (family) which I could do, I could be away on holiday with them and I don't visit the same because I am not feeling right. I don't want to be embarrassed trying to eat...I do miss the company" (p.190-191)		✓	

<p>Difficulty sharing situation with loved ones</p>	<p>"I don't see a lot of them (family) which I could do, I could be away on holiday with them and I don't visit the same because I am not feeling right. I don't want to be embarrassed trying to eat...I do miss the company" (p.190-191)</p>		<p>✓</p>	
<p>Anxiety related to lack of communication with health professionals</p>	<p>The study revealed that in some instance a lack of communication had resulted in unnecessary anxiety for the patients, this was illustrated by two participants who had received letters in the post cancelling their forthcoming therapeutic endoscopy's. No explanation had been given and both patients assumed the worst, thinking nothing more could be done for them. "Oh my God he can do no more, that's me I've had it I've had it you know" (p.1191)</p>		<p>✓</p>	
<p>Positive support from health professionals</p>	<p>"Mr [Consultant] explains things to you, I feel quite confident when he is there" (p.191)</p>		<p>✓</p>	
<p>Lack of opportunities to discuss the future</p>	<p>There were concerns about lack of information and a participant who was anxious about the deterioration in her swallowing felt there had been no opportunity to discuss her future treatment options with anyone" (p.191)</p>			<p>✓</p>

Appendix VIII



The JOANNA BRIGGS  
INSTITUTE



THE UNIVERSITY  
of ADELAIDE

School of Translational Health Science

## New JBI Grades of Recommendation

*Developed by the Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party October 2013*

JBI Grades of Recommendation	
Grade A	A 'strong' recommendation for a certain health management strategy where (1) it is clear that desirable effects outweigh undesirable effects of the strategy; (2) where there is evidence of adequate quality supporting its use; (3) there is a benefit or no impact on resource use, and (4) values, preferences and the patient experience have been taken into account.
Grade B	A 'weak' recommendation for a certain health management strategy where (1) desirable effects appear to outweigh undesirable effects of the strategy, although this is not as clear; (2) where there is evidence supporting its use, although this may not be of high quality; (3) there is a benefit, no impact or minimal impact on resource use, and (4) values, preferences and the patient experience may or may not have been taken into account.

The FAME (Feasibility, Appropriateness, Meaningfulness and Effectiveness) scale may help inform the wording and strength of a recommendation.

**F – Feasibility; specifically:**

- What is the cost effectiveness of the practice?
- Is the resource/practice available?
- Is there sufficient experience/levels of competency available?

**A – Appropriateness; specifically:**

- Is it culturally acceptable?
- Is it transferable/applicable to the majority of the population?
- Is it easily adaptable to a variety of circumstances?

**M – Meaningfulness; specifically:**

- Is it associated with positive experiences?
- Is it not associated with negative experiences?

**E – Effectiveness; specifically:**

- Was there a beneficial effect?
- Is it safe? (i.e. is there a lack of harm associated with the practice?)