

# Symptom burden and lived experiences of patients, caregivers and healthcare professionals on the management of malignant bowel obstruction: A qualitative systematic review

Palliative Medicine

1–17

© The Author(s) 2022



Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/02692163221081331

journals.sagepub.com/home/pmj



Elin Baddeley<sup>1</sup> , Mala Mann<sup>1,2</sup> , Alison Bravington<sup>3</sup>,  
Miriam J Johnson<sup>3</sup> , David Currow<sup>4</sup> , Fliss E M Murtagh<sup>3</sup> ,  
Elaine G Boland<sup>5</sup>, George Obita<sup>6</sup>, Alfred Oliver<sup>7</sup>, Kathy Seddon<sup>1</sup>,  
Anmarie Nelson<sup>1</sup>, Jason W Boland<sup>3</sup>  and Simon I R Noble<sup>1</sup>

## Abstract

**Background:** Malignant bowel obstruction occurs in up to 50% of people with advanced ovarian and 15% of people with gastrointestinal cancers. Evaluation and comparison of interventions to manage symptoms are hampered by inconsistent evaluations of efficacy and lack of agreed core outcomes. The patient perspective is rarely incorporated.

**Aim:** To synthesise the qualitative data regarding patient, caregiver and healthcare professionals' views and experience of malignant bowel obstruction to inform the development of a core outcome set for the evaluation of malignant bowel obstruction.

**Design:** A qualitative systematic review was conducted, with narrative synthesis. The review protocol was registered prospectively (<https://www.crd.york.ac.uk/prospero>, CRD42020176393).

**Data sources:** MEDLINE, EMBASE, CINAHL, PsycINFO and Scopus databases were searched for studies published between 2010 and 2021. Reference lists were screened for further relevant publications, and citation tracking was performed.

**Results:** Nine papers were included, reporting on seven studies which described the views and experiences of malignant bowel obstruction through the perspectives of 75 patients, 13 caregivers and 62 healthcare professionals. Themes across the papers included symptom burden, diverse experiences of interventions, impact on patient quality of life, implications and trajectory of malignant bowel obstruction, mixed experience of communication and the importance of realistic goals of care.

**Conclusion:** Some of the most devastating sequelae of malignant bowel obstruction, such as pain and psychological distress, are not included routinely in its clinical or research evaluation. These data will contribute to a wider body of work to ensure the patient and caregiver perspective is recognised in the development of a core outcome set.

## Keywords

Malignant bowel obstruction, qualitative research, palliative care, systematic review, intestinal obstruction, gastric outlet obstruction, cancer, neoplasms

### What is already known about the topic

- Malignant bowel obstruction is a distressing complication of advanced cancer, having a profound impact on quality of life, prognosis, and persistent, unresolved symptoms.

<sup>1</sup>Marie Curie Palliative Care Research Centre, Cardiff University, Cardiff, UK

<sup>2</sup>Specialist Unit for Review Evidence, Cardiff University, Cardiff, UK

<sup>3</sup>Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK

<sup>4</sup>University of Technology Sydney, Sydney, NSW, Australia

<sup>5</sup>Queens Centre for Oncology and Haematology, Cottingham, Hull, UK

<sup>6</sup>Dove House Hospice, Hull, England, UK

<sup>7</sup>National Cancer Research Institute, Consumer Liaison Group; Trans-Humber Consumer Research Panel, London, UK

### Corresponding author:

Elin Baddeley, Marie Curie Palliative Care Research Centre, Cardiff University, 8th Floor Neuadd Meirionnydd, Heath Park Campus, Cardiff, Wales CF14 4YS, UK.

Email: baddeleye1@cardiff.ac.uk

- Current evidence informing the palliation of malignant bowel obstruction is inadequate, and the lack of standardised clinical outcome measures for malignant bowel obstruction has resulted in inconsistent reporting and varied primary endpoints across published research in this area.
- Crucially, there is a lack of data to indicate these current outcome measures reflect what is important to people with malignant bowel obstruction, and their caregivers.

#### What this paper adds

- This qualitative systematic review highlighted the immense symptom burden and psychosocial impact of malignant bowel obstruction on patients and those around them, with wide reaching effects on a patient's quality of life.
- We identify the lack of literature regarding lived experience of patients with malignant bowel obstruction and those around them.
- Our findings demonstrate the complexities of treating patients with malignant bowel obstruction and the importance of communication between healthcare staff and these patients, and those around them.

#### Implications for practice, theory or policy

- Evaluation of malignant bowel obstruction should focus on patients' symptoms (e.g. pain, nausea) rather than undue emphasis on physiological parameters (e.g. volume of vomit).
- The psychological impact of malignant bowel obstruction on patients and their caregivers should be evaluated, and support made available as required.

## Background

Malignant bowel obstruction, defined as bowel obstruction due to cancer or its treatments, occurs in up to 15% of people with gastrointestinal cancers and 50% of people with advanced ovarian cancer (15%).<sup>1-3</sup> It is responsible for a myriad of distressing symptoms including nausea, vomiting, abdominal distension, colic, pain and constipation.<sup>3-9</sup> Consequently, it has a profound impact on patients and their caregivers' quality of life, and often requires hospitalisation for persistent, unresolved symptoms.<sup>4,10</sup> It is believed to be the commonest cause of death in people with ovarian cancer.<sup>11</sup>

Management options are limited, since most cases are not amenable to surgical intervention. Non-surgical approaches usually involve a combination of antiemetics and anti-secretory agents, often with gut drainage via nasogastric tube or venting gastrostomy.<sup>12,13</sup> The current evidence informing the palliation of malignant bowel obstruction is inadequate; clinical guidelines favour somatostatin analogues but recommendations are based largely on case series and insufficiently powered clinical trials.<sup>10</sup> Recently, two adequately powered, well-conducted clinical trials of somatostatin analogue versus usual care demonstrated no objective benefit for patients, and one suggested evidence of harm.<sup>5,14</sup> However, these studies used different primary endpoints to evaluate the efficacy of interventions; number of days from vomiting for one and proportion of patients with one or fewer episodes of vomiting per day at day 7 for the other. Four other clinical trials, albeit inadequately powered for evaluation, used a further four different primary endpoints; nausea score, absence of a

nasogastric tube, number of vomiting episodes and volume of nasogastric tube drained secretions.<sup>15</sup> The inconsistent approach to evaluating malignant bowel obstruction has resulted in varied primary endpoints across published research. Consequently, the data is not amenable to meta-analysis and guideline recommendations vary according to methodology and interpretation.<sup>16-18</sup> More importantly the outcome measures do not necessarily reflect the symptoms that people with malignant bowel obstruction consider most important to them. This had led to a call for a consistent approach to evaluating the severity of malignant bowel obstruction and its response to treatments in a way that is meaningful to those experiencing the condition.<sup>15</sup>

In order to address this knowledge gap, the Research Assessment outcome measures for Malignant Bowel Obstruction (RAMBO) study was developed. The full protocol is published<sup>19</sup> and registered with Core Outcome Measures in Effectiveness Trials (COMET; ID:1402).<sup>20</sup> The ultimate aim of this programme of work is to develop standardised, measurable outcomes that can be used by clinicians, researchers and patients/caregivers. Such a core outcome set could be used to ensure that the improvement, or progression of malignant bowel obstruction is evaluated in a consistent way, be it to evaluate the impact of an intervention, evaluate a patient's clinical status, or assess overall symptom burden. The overarching study consists of four phases: Phase I: Review of quantitative and qualitative literature, Phase II: Interviews with patients, caregivers and healthcare professionals; Phase III: Expert panel meeting to produce a list of outcomes identified through phases I and II and Phase IV: Delphi

**Table 1.** Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<p>English language only.</p> <p>Adult patients undergoing palliative treatment for malignant bowel obstruction and/or their Companions/Carers and/or healthcare professionals – all in the context of MBO.</p> <p>In-depth* reporting of patient, companion and/or HCP experiences with MBO, whether specific concept, treatment, or overall experience.</p>	<p>Under 18 years of age.</p> <p>Non-malignant bowel obstruction.</p> <p>Non-definitive MBO population – less than 70% MBO population clearly defined.</p> <p>Published before 2010.</p> <p>Purely outcomes of a quantitative nature, regarding survival, resolution of symptoms as recorded by clinical professionals regarding a patient.</p> <p>QoL tools with no in-depth experiences.</p>

\*In-depth: interviews, focus groups, patient diaries, descriptive open-ended questionnaire, etc.

surveys to refine the outcomes, and consensus meeting to ratify those outcomes.

In this paper we report the findings of a systematic review of qualitative studies pertaining to the views and experiences of patients, caregivers and healthcare professionals, about malignant bowel obstruction. The decision to report these data separately follows recommendations of our Patient and Public Involvement partners who felt it important to ensure the patients' and caregivers' voices were presented clearly and not lost in the data of a larger report. The findings of a systematic review of the quantitative literature will be reported in a separate paper.

## Methods

This review was conducted in accordance with the Palliative Care Evidence Review Service (PaCERS) modified systematic review methodology.<sup>21</sup> This review uses modified systematic review methods in which components of the review process are streamlined, in particular the time frame, which was decided upon due to the striking lack of existing literature before 2010, which was identified from a scoping search undertaken prior to the conduction of the review. The review was prospectively registered with the International Prospective Register of Systematic Reviews on 30th March 2020, ID: CRD42020176393, and is reported following the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines.<sup>22,23</sup>

### Review question

The review question was '*what are the views and experiences of people with malignant bowel obstruction, their caregivers, and healthcare professionals providing care to people with malignant bowel obstruction?*'.

### Search strategy

A systematic search of the following databases between January 2010 to May 2021: MEDLINE, EMBASE, CINAHL, PsycINFO and Scopus. Grey Literature: OpenGrey and

CareSearch. We also carried out forward citation tracking of included studies in Google Scholar. We searched for papers published, in English language publications. To address the research question, the search strategy focussed on three concepts (see Supplemental Appendix 1 for full search strategy). Searches were conducted combining search strings for (a) bowel obstruction search terms (e.g. intestinal obstruction, bowel obstruction), (b) adult population diagnosed with malignant bowel obstruction (e.g. ovarian neoplasm or colorectal neoplasm) and (c) study types capturing views and experiences with at least some qualitative data, such as views and experiences (e.g. views, experiences, semi-structured interviews).

### Study selection

Papers identified by the searches were downloaded into Endnote and duplicates removed. Criteria for inclusion/exclusion are summarised in Table 1. Following an initial screen to remove duplicate references and irrelevant articles (paediatric, non-cancer), the titles and abstracts of remaining references were independently dual-screened for inclusion (EB, MM). Disagreements were adjudicated by a third reviewer (SN). Full-text articles were retrieved, independently dual-screened (EB, MM), with a third reviewer available to adjudicate discrepancies (SN).

### Data extraction

A standardised data extraction form was developed (see Supplemental Appendix 2). Data extraction was completed by one reviewer (EB) and checked/edited by a second reviewer (MM). Any differences in the data extraction were resolved through discussion, with an independent reviewer consulted where needed (SN).

### Quality assessment

Included studies underwent quality assessment using the appropriate checklist from the Specialist Unit for Review

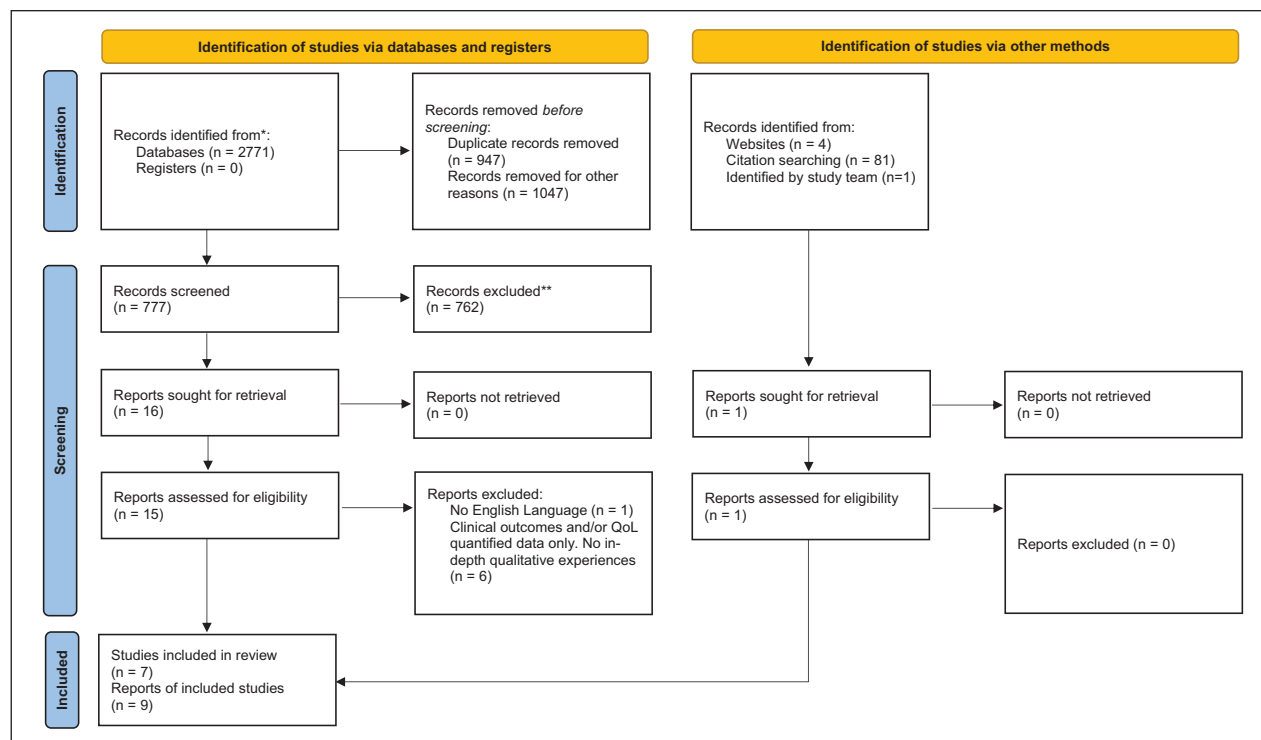


Figure 1. PRISMA<sup>23</sup> flow diagram.

Evidence.<sup>24</sup> Where a number of papers reported the same study, quality was assessed once for the overall study. Qualitative research papers should describe appropriate sampling, data collection and analysis. The checklist included 10 questions, relating to methods, reflexivity and ethical practice. These assessments allowed the reviewer a systematic approach to evaluating the strength and reliability of the evidence (Supplemental Appendix 3). The quality of the included papers were similar, therefore our analysis did not require weighting towards any of the papers.

### Data synthesis

In view of the heterogeneity of the included studies, a narrative synthesis approach was used to integrate and describe the results.<sup>25</sup> Data were synthesised by comparing findings from each of the nine papers. The themes identified in the papers were preliminarily grouped, followed by analysis of specific quotations within the themes from each of the papers. These quotes and themes across all nine papers were then grouped by their similarities and their differences, with the final stage being the generation of overarching themes by the reviewers, to group specific elements covered within each of the papers of the views and experiences of patients with malignant bowel obstruction, their caregivers, and healthcare professionals. The empirical data from the 'results' or 'findings'

section in the included studies were extracted and synthesised (EB and MM).

### Results

The searches generated 777 papers after removing duplicates and irrelevant articles. The search results, are summarised in a PRISMA flow diagram in Figure 1. Of a total of 16 papers screened for eligibility, seven studies (nine papers) were included in the final narrative synthesis<sup>26–34</sup> and are described in Table 2, with a summary of study participants in Table 3. Seven papers were excluded because they did not report in-depth qualitative experiences, but instead described data from validated questionnaires or retrospective clinical note review ( $n = 6$ )<sup>35–40</sup> and not having English language translation available ( $n = 1$ ).<sup>41</sup> Major themes and associated subthemes of the included nine papers are summarised in Figure 2 and described in the subsequent results section below. Additional quotations are presented in Table 4.

#### Theme 1: Symptom burden

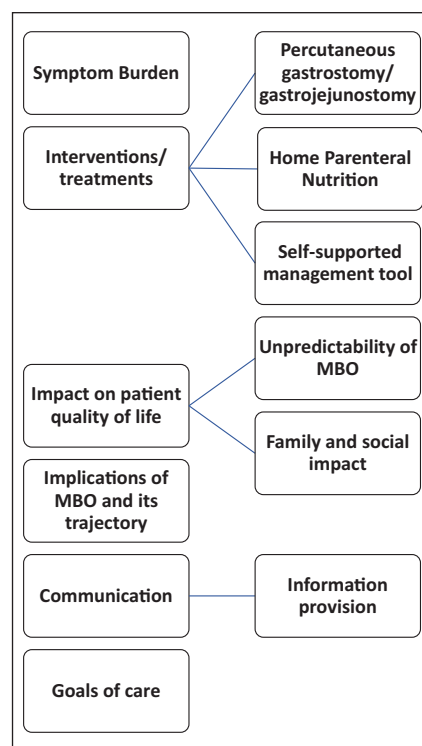
One paper described symptoms of malignant bowel obstruction in detail; the paper reported that 'pain' was mentioned by the majority of patients (18/20 participants), closely followed by 'vomiting' (13/20), 'bloating' (12/20), 'discomfort' (9/20) and 'nausea' (8/20).<sup>34</sup> Three

**Table 2.** Characteristics of included papers.

Authors	Country	Perspective	Intervention/ exposure being explored (in context of MBO)	Participant no.	Data collection	Methodology	Analysis	Main findings
Cusimano et al. <sup>26</sup>	Canada	Patient	Self-supported management tool	N = 15	Intervention (single arm trial) and semi-structured interviews	Descriptive methodology	Descriptive methodology – Chronic Care Model Framework	Self-supported management tool helped patients feel empowered, more in control and well supported; palliative care (PC) involvement was positive, although those who had not had PC support associated PC negatively; lack of recognition of disease trajectory and terminal nature evident. Highlighted the emotional and physical challenges patients with MBO face (from nurse perspective). There is limited qualitative research in this area; more work is required to understand the phenomena for patients, their carers' and HCPs. MBO diagnosis impacts patients immensely; in particular, a loss of self. Encouraging open, non-interrogatory dialog can support patients through this, however there is limited time to do so. Expectations of palliative care consultations varied. Strengthened communication to involve palliative care is recommended.
Daines et al. <sup>27</sup>	Canada	HCPs – Nurses	Overall experiences	N = 15	Semi-structured interviews and focus groups	Not stated	Descriptive approach	Impact of PVG on individuals is highly unique to a person; service improvement was key, including more information and training for HCPs to overcome the barriers.
Gwilliam and Bailey <sup>28</sup>	UK	Patients	Patients' lived experiences	N = 10	Semi-structured interviews	Phenomenology	Not stated	Burden of treatment did not outweigh the benefits HPN provided and recognised it as a lifeline. HCPs do however need to make sure losses are clear to patients and be alert to them. HPN cannot address the non-nutritive aspects of food; although some patient cope better with this loss, the loss is still profound, and HCPs need to be aware and provide appropriate support.
Hoppenot et al. <sup>29</sup>	US	HCPs – Gynaecologic oncologists	Palliative care consultation decision making	N = 15	Interviews	Not stated	Framework analysis	There is a discrepancy in oncologist and patient perspectives in how the treatment decisions are made. However, this does not mean patients were coerced; instead, it is important to provide patients with enough information to fully understand the implications of HPN.
Singh Curry et al. <sup>30</sup>	UK	Patients	Percutaneous venting gastrostomy/gastrojejunostomy (PVG)	N = 10	Semi-structured interviews	Not stated	Framework analysis	There is an almost complete lack of research in patients with Gastrointestinal obstruction (qualitative). Symptom burden is high, and a concept domain for a PRO measure has been developed to measure this.
Sowerbutts et al. <sup>31</sup>	UK	Patients	Home parenteral nutrition (HPN)	Patients = 20 Caregivers = 13 HCPs = 32	Mixed methods – including Qualitative semi-structured interviews	Hermeneutic phenomenology	Thematic principles guided by Van Manen	
Sowerbutts et al. <sup>32</sup>		Patients and caregivers	HPN – dealing with eating loss		Qualitative semi-structured interviews	Phenomenology		
Sowerbutts et al. <sup>33</sup>		Patients, caregivers, HCPs	HPN – discharging decision		Qualitative semi-structured interviews	Phenomenology		
Williams et al. <sup>34</sup>	US	Patients	Symptom burden	N = 20	Interviews	Not stated	Not stated	

**Table 3.** Demographics of participants.

	Patient demographics (seven studies)	HCP demographics (three studies)	Companion demographics (one study)
Gender (pts)	Female = 81% (61) Male = 16% (12) Unknown = 3% (2)	Refs. 24, 25, 29, 30, 31, 32, 33 Nurses = 47% (29) Oncologist = 31% (19) (15 gynae) Dieticians = 16% (10) Doctors = 3% (2)	Refs. 26, 27, 33 Relationship to patient Husband = 62% (8) Daughter = 31% (4) Son = 7% (1)
Age (pts)	Mean Age = 62 years old		
Cancer diagnosis	Ovarian = 57% (43) Colorectal = 13% (10) Gastric = 7% (5) Urothelial/renal = 4% (3) Uterus = 3% (2) Cervical = 3% (2) Appendiceal = 3% (2) 'Other' = 9% (7) Unknown = 1% (1)	Gastroenterologist = 1.5% (1) Intestinal failure support manager = 1.5% (1)	

**Figure 2.** Themes and associated sub-themes.

other papers described the symptoms of malignant bowel obstruction in less detail but highlighted the debilitating and distressing impact that symptoms had on both patients and families, particularly symptoms of pain, nausea, and vomiting.<sup>26,27,29</sup> For example, nurses interviewed<sup>27</sup> in one study identified the far-reaching impacts of these distressing symptoms on not just the patient, but their family members also: *"They have pain, discomfort, nausea, vomiting and transcends to the families."* Nurse, page 596.<sup>27</sup> One patient described the pain they experienced as an endless, debilitating feeling *"very painful. It consists of like being stuck with a knife or pin, and at times it just goes on and on."* Patient, table 3,<sup>34</sup> while another patient commented on the vomiting they experienced, which resulted in feelings of distress: *"As soon as my stomach reached a certain point, I vomited. So, the vomiting was distressing."* Patient, table 3.<sup>34</sup>

The data reported in detail that the 'most common and most distressing' issue experienced by patients was how malignant bowel obstruction impacted on eating and overall food intake.<sup>29</sup> This was a multifaceted and complex impact of malignant bowel obstruction, viewed as much a social and emotional loss for patients, as being considered a physical issue. Losses included greatly missing the sensation of food: *"When I look at those fruit bowls. . . , and I just see these shining grapes and shining nectarines there, I just see myself biting into that nectarine. . ."* Patient, page 478,<sup>28</sup> to the isolation felt from being unable to enjoy a meal in a social situation: *"I mean, if you can't do*



**Table 4.** Summary of quotations.

Themes/topics	Quotations	Author interpretations (from included studies)
Symptoms ( <i>n</i> = 4) <sup>24,25,27,32</sup>	<p>“They have pain, discomfort, nausea, vomiting and [this] transcends to the families. . .” [Daines et al; Nurse, page 596–597].</p> <p>“Patients are in the top tier of effort-intensive care, because of the nature of a bowel obstruction is that it’s intractable, and it’s invariably nauseating and pain-causing.” [Hoppenot et al; Gynaecologic Oncologist, Table 4].</p> <p>“I was in such pain. I went to see her, and I said – read this – I can no longer go on like this” [Cusimano et al; patient, Table 3].</p> <p>“I just feel very, very uncomfortable. . . any second now I’m going to blow up or throw up.” [Williams et al. patient, Table 3].</p> <p>“Physically it was distressing, because – I was not able to keep any food down. . . the vomiting was distressing.” [Williams et al; patient, Table 3].</p>	<p>Treatment of the patient with MBO is challenging and influenced by [a variety of] factors. . . nurses commented on the challenges inherent in controlling symptoms through a variety of strategies. [Daines et al; page 596].</p> <p>Eight of 15 gynaecologic oncologists pinpointed MBO as one of the top 5 difficult situations in gynaecologic oncology. . . Two oncologists in particular struggled with the increase in symptom management needs of the patient, particularly nausea and pain. [Hoppenot et al. page 4].</p> <p>Participants experienced severe physical symptoms as a result of MBO. Pain, nausea, vomiting and distension were universal. . . limited participants’ quality of life and autonomy. [Cusimano et al, page 3].</p> <p>Nine symptoms were reported by more than 20% of patients: 4 MDASI Core symptoms and 5 GIO-specific symptoms. . . patients reported symptom interference with life activities, such as general activities, work, walking, relations with others, mood, and enjoyment of life. [Williams et al, page 3].</p>
Intervention ( <i>n</i> = 5) <sup>24,28–31</sup>	<p>Home Parenteral Nutrition (HPN)</p> <p>“It’s either die with food or [HPN]. . . I’d sooner live and be on [HPN]” [Sowerbutts et al 2019, patient, page 5].</p> <p>“It’s keeping her alive really. That’s the big advantage.” [Sowerbutts et al 2019. Family member, page 6].</p> <p>“It wasn’t as easy as it was made out to be.” [Sowerbutts et al, 2019. patient, page 7].</p> <p>Percutaneous Venting Gastrostomy (PVG)</p> <p>“they explained that it would be helpful for the sickness. . . stopping the sickness, which it did. I was so grateful for that.” [Singh-Curry et al. patient, page 385].</p> <p>“has been in a lot of discomfort, it has been leaking all the time, he’s being changed numerous times a day. . . now his skin is all sore” [Family member] [Singh-Curry et al, caregiver, page 386].</p> <p>“when I go in the shower and everything, I can. . . take both tubes off, and I’m a different person.” [Sowerbutts et al. 2019, patient, page 7].</p>	<p>Women viewed HPN as a ‘lifeline’ . . . not only improving their quantity, but also their quality of life as they could be out. . . home with friends and family. . . [however] progression and HPN gradually eroded patients’ ability to undertake activities of daily living. [Sowerbutts et al. 2019. Page 5].</p> <p>Patients discussed two main positive impacts of PVG on their life: amelioration of symptoms and enabling their NGTs [nasogastric tube] to be removed. . . All reported that their nausea and vomiting either reduced or subsided completely PVG insertion. . . There were some challenges. . . practical issues, psychosocial issues, pain and PVG tube complications. [Singh-Curry et al, page 385].</p> <p>Some patients found the most restrictive aspect was their venting gastrostomy. The HPN was only attached overnight, whereas they were only free from the gastrostomy when they were showering. [Sowerbutts et al 2019, page 7].</p>

(Continued)

Table 4. (Continued)

Themes/topics	Quotations	Author interpretations (from included studies)
Patient impacts ( $n = 6$ ) <sup>24-27,29,30</sup>	Nasogastric Tube (NGT) "I hated that up my nose because it was so uncomfortable." [Singh-Curry et al. patient, page 385].	Removal of their NGTs was seen as a benefit after PVG insertion; improving their comfort, body image and dignity. [Singh-Curry et al. page 385].
	Self-management tool "I learned how to assess bowel movements to determine what is a healthy bowel movement and what is evidence that there's possibly a problem coming up." [Cusimano et al. patient, Table 3]. "So, yeah, learned a lot. Thank God." [Cusimano, et al. patient, Table 3].	The MBO program ensured that participants knew: (1) why they were occurring, (2) how to prevent them and (3) how to respond to them appropriately. [Cusimano et al, page 3].
	Psychological/emotional "my outlook on life changes day-to-day. . . I feel so healthy in many ways. But then I will get this obstruction and that changes everything suddenly. It's scary. It's a rollercoaster." [Cusimano et al. Patient, Table 3]. "Now what's going to happen when I go home? Am I going to be able to eat? What if I eat and I start to throw up?" [Daines et al. Nurse, page 595]. "I just miss food. . . you find yourself dreaming about daft things. . ." [Sowerbutts et al 2020a. patient, page 4]. "just wanting to get back to normal, if you see what I mean, whatever normal is these days." [Sowerbutts et al. 2020a. patient, page 4]. "It's hard to patients to go through bowel obstructions." [Hoppenot et al. Gynaecologic oncologist, Table 2]. "They need the psychosocial." [Hoppenot, et al. Gynaecologic Oncologist, Table 2]. "My ability to construct. . . logical propositions, sometimes, is gone. . . the treatment, can make me hallucinate. . . I can't be sure, when I close my eyes, whether I'm in a real situation [or not]." [Gwilliam et al; Patient, page 478]. Family/Social "The roles and relationships really change too as they deteriorate, and the families have a greater sense of burden having to take on more." [Daines et al. Nurse, page 595]. "You can't expect anybody to understand who's not got to do it." [Sowerbutts, et al. 2020a. patient, page 4].	Fear, uncertainty and powerlessness were pervasive and highly distressing to participants, and stemmed largely from the unpredictable nature of MBO. Even when physically well, participants remained on edge. [Cusimano et al. page 6]. A variety of emotions were identified including uncertainty, fear, sense of burden and guilt. [Daines et al, page 595]. The loss of being able to eat was profound for the patients. . . they expressed an emotional loss, as eating is associated with normality. [Sowerbutts et al 2020a, page 4]. They considered. . . psychological support to be part of their job. . . but consulted palliative care teams when the situation went beyond their skillset. [Hoppenot et al. page 2-3]. Patients described being unable to focus or make sense of what was happening to them. Some described themselves as 'switching off' or withdrawing. . . reflects a total loss of selfhood. [Gwilliam et al, page 477]. Nurses' described patients' 'uncertainty' around the unknown and the yet-to-come, and the impact of this on their families. [Daines et al. page 595]. They felt excluded from the activity of eating but also socially isolated as it was difficult for others to understand their situation. [Sowerbutts et al 2020a, page 4].

(Continued)



**Table 4.** (Continued)

Themes/topics	Quotations	Author interpretations (from included studies)
Nature/Trajectory of MBO (n = 4) <sup>24-27</sup>	<p>"They're not even cooking a Christmas dinner. . . and that upsets me for them." [Sowerbutts et al 2020a, patient, page 4].</p> <p>"Look at her sitting in that room can't have [anything] and look at me shovelling all this in'. . . it's mental strain on him. . . he's lost a bit of weight." [Sowerbutts et al 2020a, patient, page 3-4].</p> <p>"if you can't do anything else but die, at least you expect to have a few meals with your relatives don't you?" [Gwilliam, et al. patient, page 476].</p> <p>"I laid on the bed. . . I didn't want to move, to go in and out like I normally would, to socialise." [Gwilliam et al. patient, page 478].</p> <p>"I can't meet my friends for a drink now and I miss them. . . sometimes I think people will forget about me here." [Gwilliam et al; patient, page 478].</p> <p>Normality</p> <p>"I went in the garden the other day and did a bit of tidying up." [Sowerbutts et al, 2019. Patient, page 6].</p> <p>"I've sorted all Christmas out." [Sowerbutts et al. 2019. Patient, page 6].</p> <p>"It really annoys me that I can't join in things." [Sowerbutts, et al. 2020a. patient, page 4].</p> <p>"Become so weak" [Gwilliam et al. patient, page 478].</p> <p>Can't "wash themselves" [Gwilliam et al; patient, page 478].</p> <p>Nature of MBO</p> <p>"is this going to happen every few weeks? So, I might be fine for a while. I don't know, they don't know either" [Cusimano, et al. patient, Table 3].</p> <p>"You also can't predict completely how things are going to go. . . so, I think the unknown for the patient is really hard." [Hoppenot, et al. Gynaecologic oncologist, Table 4].</p> <p>Trajectory of MBO</p> <p>"But it [MBO] doesn't result in dying all that quickly." [Hoppenot, et al. Gynaecologic oncologist, Table 4].</p>	<p>Her husband, however, felt guilty eating around his wife. [Sowerbutts et al 2020a, page 3].</p> <p>When at home, some women could not tolerate people eating in front of them. [Sowerbutts et al 2020a, page 3].</p> <p>[One patient] was sad about the impact that this had on her family who she perceived had lost their traditional way of celebrating Christmas. [Sowerbutts et al 2020a, page 4].</p> <p>Being unable to eat. . . was the most common and most distressing problem for all the patients. This was perceived as more of a social and emotional loss than a biological one. . . loss of social contact and relevance, particularly with friends and family. [Gwilliam et al, page 476].</p> <p>'Social isolation' describes how patients felt unable to participate in interpersonal relationships and wider social networks. . . old friends were described as 'being distant'. . . eating and drinking are often linked with socialising. . . barrier to social interaction. [Gwilliam et al. page 478].</p> <p>It was important for patients having aspects of their life that were unchanged by their illness. [Sowerbutts et al, 2019. Page 6].</p> <p>This lack of normality made the women feel isolated. [Sowerbutts et al 2020a, page 4].</p> <p>Patients referred frequently to the loss of function and independence as opposed to the effects of symptoms. . . become physically dependent and were in a sense not fully 'themselves'. [Gwilliam et al. page 478].</p> <p>[MBO] fluctuated unpredictably between periods of total and partial obstruction. [Cusimano et al. page 3].</p> <p>[Some] struggled with the shift in goals of care and the complexity of counselling that an MBO diagnosis presaged. [Hoppenot et al, page 4].</p> <p>[Some] struggled with the increase in symptom management needs of the patient, particularly nausea and pain over a long period of time. [Hoppenot et al. page 4].</p>

(Continued)

Table 4. (Continued)

Themes/topics	Quotations	Author interpretations (from included studies)
	<p>"I'm not planning for, you know, three years down the road. I have a very bad cancer, but I don't let it affect me. I know to plan six months, or a year ahead." [Cusimano et al. patient, Table 3].</p> <p>"Dealing with how long they're going to be here. . . it makes them reflect and decide what they have to do, sometimes there is urgency to look after certain things within their family life. . ." [Daines et al. Nurse, page 597].</p> <p>"Well, I did feel that they didn't believe me and I was fobbed off, very much so. . . and now I have had no respite. . . my symptoms have been continuously getting worse ever since." [Gwilliam et al; patient, page 479].</p> <p>Sense of support</p> <p>"I know that there is somebody to reach out to. So they know how to deal with my problem. So that is the support I think I need." [Cusimano et al. patient, Table 3].</p> <p>"They're not just leaving you in the lurch to figure it out yourself." [Cusimano et al. patient, Table 3].</p> <p>"When it's difficult to get answers. . . and they say. . . "we don't know" or there's no answer to it. . . you feel then, that you're just being abandoned." [Gwilliam et al; patient, page 479].</p> <p>Treatment decisions</p> <p>"It's about having that discussion with the patient. . . trying to help the patient make their own individualised decision of what we feel is in their best interest." [Sowerbutts et al 2020b, Oncologist, page 4].</p> <p>"There was no choice really, it was one of those take it or leave it." [Sowerbutts et al 2020b, patient, page 4].</p> <p>Information/care provision</p> <p>"one nurse who was giving it a clean said, you don't rotate this one [PVG]. . . that other nurse, she said something about I'll rotate it and I said oh well, I've been told not to rotate mine." [Singh-Curry, et al. patient, page 386].</p>	<p>Patients recognised that their condition was terminal and had accepted their own mortality. . . [although] none truly believed that they could be within weeks from death. . . limited understanding of natural trajectory of MBO and its impact on their prognosis. Some did not internalise that MBO was tied to cancer progression and would never completely resolve. [Cusimano et al. page 6].</p> <p>When MBO [malignant bowel obstruction] is diagnosed, the prognosis is often poor and the trajectory unpredictable, forcing patients and families to make end-of-life care decisions unexpectedly. [Daines et al. page 597].</p> <p>Despite the severity of their illness and their weakness, they described in detail the onset of their illness, difficulties with being acknowledged by healthcare services and the relentless nature of their illness and deterioration. [Gwilliam et al. page 479].</p> <p>The efforts of oncology nurses in monitoring enrolees and staffing a dedicated phone line were particularly critical in alleviating participants' anxiety. . . participants also stressed the importance of the nurses themselves initiating regular phone calls. [Cusimano et al. page 6].</p> <p>'doing something' appears to be a way of maintaining hope for patients. 'Doing nothing' could be seen as abandonment or desertion. [Gwilliam et al. page 479].</p> <p>The decision for HPN was driven by oncologists. . . they discussed HPN with patients that were deemed suitable and the individual made their own decision. . . patients presented an alternative view reporting the doctor had recommended it or had made the decision based on clinical necessity. [Sowerbutts et al 2020b, page 4].</p> <p>One patient was given conflicting information regarding the care of her PVG. One patient did not feel confident in the way that the HCPs cared for her PVG tube and some felt that they were not supported by HCPs to facilitate their autonomy in caring for their PVG. [Singh-Curry et al. page 386].</p>

(Continued)

**Table 4.** (Continued)

Themes/topics	Quotations	Author interpretations (from included studies)
	<p>“We used to have patients sat in for six to eight weeks [facilitating HPN] . . . but two weeks is quite amazing for me.” [Sowerbutts et al 2020b, palliative care nurse, page 5].</p> <p>“It’s the start bit that takes the time.” [Sowerbutts, et al 2020b, nurse, page 5].</p>	<p>Healthcare professionals discussed measures put in place over the years, which might have reduced discharge time, such as improved communication between staff. This occurred by increasing opportunities for face-to-face meetings. . . an additional benefit was improved communication and strengthened relationships between dieticians and doctors. . . poor communication between healthcare professionals was a potential barrier, given the number of people involved. . . distance meant that communication. . . lacked continuity. [Sowerbutts et al 2020b, page 5].</p>
Goals of care (n = 3) <sup>22,26,27</sup>	<p>Conflicting goals</p> <p>“I do use palliative care a lot when I think the patient and their family and I are not on the same page at all.” [Hoppenot et al. Gynaecologic oncologist, Table 2].</p> <p>“It’s almost a Catch-22, because you put them to the toilet and you make the family happy, but you’re not making the patient happy because the patients’ exhausted.” [Daines, et al. Nurse, page 596].</p> <p>Collaboration/Facilitation of goals</p> <p>“There are these last wishes and these last desires that you want to be able to satisfy. . . so we spend a lot of time just talking about: what does it mean? What’s happening? What do you need?” [Daines, et al. Nurse, page 596].</p> <p>“opportunities to talk about the plans for what’s going to happen next, a lot of communication between the doctors and the family and the rest of the multidisciplinary team.” [Daines, et al; Nurse, page 596].</p> <p>“You are lost for direction. . . just left on your own.” [Gwilliam et al; patient, page 479].</p>	<p>Most gynaecologic oncologists consulted the palliative care team for specific aspects of care, such as symptom control, goals-of-care conversations or psychological support. [Hoppenot et al, page 2].</p> <p>Nurses stated that they were constantly challenged to find the right balance between what the patient needed and what the family thought was best for the patient. [Daines et al, page 596].</p> <p>Nurses conveyed a real desire to try and help patients achieve their last wishes and to make a difference in how patients were spending their last days. [Daines et al. page 596].</p> <p>Nurses emphasised their important role in transdisciplinary care. . . they appreciated opportunities to discuss care plans with their colleagues. [Daines et al, page 596].</p> <p>Having a goal was important and meant that something was being done. [Gwilliam et al. page 479].</p>

anything else but die, at least you expect to have a few meals with your relatives, don't you?" Patient, page 476.<sup>28</sup>

Fatigue and disturbed sleep were reported by six of the 20 patients interviewed in one paper.<sup>34</sup> Whilst not described explicitly in other papers, several studies reported general 'weakness', trouble sleeping and lack of physical energy.<sup>28,31,34</sup> A patient from one paper commented on the lack of undisturbed sleep *"It would be wonderful if I could have even 5 h sleep without a break."* Patient, page 6,<sup>31</sup> while a patient from another paper described how the pain (from cramps) and lack of food intake contributes to their fatigue: *"It's intense cramps, basically with the effect that you don't eat, which makes you weaker. Most cramps come at night, so you get very tired. . . The whole process wears you out."* Patient, table 3.<sup>34</sup> However, it was difficult to establish whether these symptoms were symptoms of malignant bowel obstruction, its treatments and their side effects, or from the underlying primary malignancy itself.

While one of the papers<sup>34</sup> was the only paper which focussed on symptoms specifically and in detail, many of the papers identified symptoms of malignant bowel obstruction and its devastating impact. The most commonly expected symptoms, such as nausea, vomiting and pain, were prevalent in the qualitative literature. Other symptoms/side effects included eating and drinking inability, general weakness/fatigue, and inability to have a bowel movement.

### Theme 2: Interventions/treatments

Four papers (reporting on two studies), offered patient, caregiver, and healthcare professional perspectives on the following interventions; percutaneous venting gastrostomy/gastrojejunostomy and home parenteral nutrition.<sup>30–33</sup> One other paper looked at patients' experiences of a self-management intervention; an educational tool to educate patients on malignant bowel obstruction.<sup>25</sup>

*Percutaneous gastrostomy/gastrojejunostomy.* Patients described both positive and negative aspects of receiving a percutaneous venting gastrostomy/gastrojejunostomy. All participants experienced reduced or completely resolved nausea and vomiting, with some also reporting reduced pain and abdominal distension: *"They explained it would be helpful for the sickness. . . stopping the sickness, which it did. I was so grateful for that because it was just projectile all the time."* Patient, page 385.<sup>30</sup> Another positive aspect of percutaneous venting gastrostomy/gastrojejunostomy insertion was that the nasogastric tube could be removed, thereby improving body image and comfort: *"I hated that up my nose because it was so uncomfortable. It hurt me. . ."* Patient, page 385.<sup>30</sup>

Negative experiences were also described. These included leaking issues, post-procedure pain, anxiety over perceived 'smells' and reduced mobility,<sup>31</sup> which one

patient described: *"You can smell it though, even if it's not leaking. I feel like. . . it smells like sewage. . ."* Patient, page 386.<sup>30</sup> One patient described the 'freeing' sensation, when for brief periods, they could remove all the tubes they were attached to: *"When I go in the shower and everything I can. . . take both tubes off, and I'm a different person"* Patient, page 7.<sup>31</sup> Other negative aspects included patients considering a venting gastrostomy/gastrojejunostomy as a constant presence; some were afraid to eat, for fear of causing a blockage of the tube.<sup>31,32</sup>

*Home parenteral nutrition.* Patients viewed home parenteral nutrition as a 'lifeline', increasing both survival and quality of life. Patients mentioned being able to be at home, achieve some normality and spend time with family.<sup>31</sup> Healthcare professionals also felt positive towards home parenteral nutrition as an intervention and its benefit: *"You are. . . giving precious time to people when there are things that they want to do and HPN allows them to do that."* Palliative Care Nurse, page 4.<sup>33</sup> However, home parenteral nutrition, like percutaneous venting gastrostomy/gastrojejunostomy, came with its challenges and losses. This included a profound loss of normality, limited bodily freedom and energy: *"It's difficult, yeah, especially going upstairs, because I've not got much energy."* Patient, page 6,<sup>31</sup> imposed routine and invasion of medical environment into the home.<sup>30</sup> One patient described the experience as more difficult than they anticipated: *"It wasn't as easy as it was made out to be."* Patient, page 7.<sup>31</sup>

Other papers highlighted the uncertainty of success and difficulties choosing between treatments. One nurse described the 'vicious cycle' of interventions experienced by patients: *"It seems like a vicious circle for these patients. . . they end up having all kinds of interventions. . ."* Nurse, page 597,<sup>27</sup> whereas an oncologist highlighted the difficulties of presenting intervention options to patients, when the uncertainty of success is so high: *"Having to help them decide between two options when there's no clear answer, the emotional is higher."* Gynaecological Oncologist, table 4.<sup>29</sup>

Overall, management of malignant bowel obstruction is described as complex when reported by healthcare professionals and intervention experiences reported by patients are mainly positive for patients in regard to symptom alleviation and perceived quality of life/quantity of life gains; however, all come with their challenges and loss to some quality of life, particularly interrupting their ability to achieve normality through simple daily activities and social interactions.

### Theme 3: Impact on patient quality of life

The psychological and emotional toll of malignant bowel obstruction on patients and their family, is considerable. A major contributory factor was the uncertainty of

healthcare professionals around unpredictable disease trajectory and life expectancy.

*Unpredictability of malignant bowel obstruction.* The unpredictable nature of malignant bowel obstruction and its uncertain trajectory led to feelings of powerlessness and fear.<sup>26</sup> The unpredictability of the condition, in particular, waiting around for their obstruction to resolve, or their treatment to come into effect, was a particular source of emotional turmoil within patients.<sup>27,28</sup> One patient described their frustrations of waiting for their obstruction to resolve: *"I don't think I could face this week, I think I would go completely off me head, facing up to the weekend, to be told, 'well, just sit tight, have your fluids.'" Patient, page 479,*<sup>28</sup> and one nurse described patients' worry and uncertainty of what will happen to them when they get home, with no resolution of the obstruction: *"Now what's going to happen when I go home? Am I going to be able to eat? What if I eat and I start to throw up?" Nurse, page 595.*<sup>27</sup>

One paper also identified deterioration in mental ability, inability to focus, withdrawing from oneself and also disengaging from their loved ones surrounding them: *"My ability to construct. . . logical propositions, sometimes, is gone. . . I can't be sure, when I close my eyes, whether I'm in a real situation or just something I'm thinking about." Patient, page 478.*<sup>28</sup>

As mentioned above, fear of the unknown and what will happen next in their trajectory was a source of emotional turmoil and psychological 'rollercoaster' of emotions: *"I feel so healthy in many ways. But then I will get this obstruction and that changes everything suddenly. It's scary. It's a rollercoaster." Patient, page 478.*<sup>26</sup> The ups and downs of the trajectory of malignant bowel obstruction and the uncertainty for healthcare professionals was particularly a source of stress: *"Is this going to happen every few weeks? And my doctor said – well it can, but we don't know for sure. So I might be fine for a while. I don't know, they don't know either." Patient, table 3.*<sup>26</sup>

*Family and social impact.* Malignant bowel obstruction impacted on relationships within the family, including family mealtimes and other social activities. One paper highlighted the sense of burden patients feel they are weighing down on their families: *"The roles and relationships really change too as they deteriorate and the families have a greater sense of burden having to take on more." Nurse, page 595.*<sup>27</sup> Family mealtimes and most social events revolve around eating and/or drinking, thereby resulting in impacts on the patient and the family,<sup>28,32</sup> such as reduced social interactions: *"I can't meet my friends for a drink now and I miss them. . ." Patient, page 478*<sup>28</sup> and avoiding family members during mealtimes: *"B. has his meals in the kitchen, so I don't go in there while he's (eating)." Patient, page 3.*<sup>32</sup>

Several patients highlighted the social isolation that came with the condition; feeling isolated, whether from their own choice: *"I laid on the bed. . . I didn't want to move, to go in and out like I normally would, to socialise. I had people come up. I wasn't very amenable. . ." Patient, page 478*<sup>28</sup> or due to the way they felt: *"You're sort of isolated, on your own. You're not, but that's how you feel. . . you do feel. . . you do feel that you are in a little place, just left on your own." Patient, page 479.*<sup>28</sup>

A diagnosis of malignant bowel obstruction has a profound effect on patients, who are coming to terms with a distressing condition, in addition to, and because of their cancer diagnosis. The emotional toll and impact on a patients' mental wellbeing are overwhelming, and difficult to mitigate, due to the uncertain nature of each individual case of malignant bowel obstruction. The impact of this diagnosis on a patients' routine, including family and social life, is shown in the literature to have been impacted severely.

#### *Theme 4: Implications of malignant bowel obstruction and its trajectory*

The trajectory or clinical course of malignant bowel obstruction is poor and indicates that the underlying cancer is most likely at an advanced stage and progressing. The deterioration can be swift, forcing patients and their families to make decisions promptly and face the limited time that they have left: *"Dealing with how long they're going to be here. . . it makes them reflect and decide what they have to do. . ." Nurse, page 597.*<sup>27</sup>

Patients appeared to struggle with the lack of instant results and the direction their condition was heading; in particular, the uncertainty even among healthcare professionals managing the condition.<sup>26–29,33</sup> For example, one patient described the difficulty in receiving answers from healthcare professionals: *"When it's difficult to get answers. . . and they say. . . 'we don't know' or there's not answer to it. . . you feel then, that you're just being discarded." Patient, page 479.*<sup>28</sup>

The variability of patients is clear in that patients are highly unique, and healthcare professionals are unable to provide clear or certain information on how the patients' condition will unfold. This appears to add to frustrations for patients.

#### *Theme 5: Communication*

*Information regarding malignant bowel obstruction.* Patients appreciated nurses' help making sense of their diagnosis and condition by providing them with support and information: *"They're not just leaving you in the lurch to figure it out yourself but checking if you need anything further or have any questions." Patient, table 3.*<sup>26</sup>



Similarly, the previously described self-management tool evaluated in one paper,<sup>26</sup> appeared to address support and information needs: *"I have my handouts. . . it's like my bible. I check it all the time."* Patient, table 3<sup>26</sup>; it empowered patients and provided them with ways to self-manage: *"I learned how to assess bowel movements to determine what is a healthy bowel movement and what is evidence that there's possibly a problem coming up"* Patient, table 3<sup>26</sup> but all the while knowing they instantly had the healthcare professionals' support.<sup>27</sup>

*Information regarding proposed interventions.* Patients undergoing placement of a percutaneous venting gastrostomy felt that they were given insufficient information prior to the procedure, and that details provided were sometimes conflicting: *". . . when I got down to radiology, Dr X came and explained it all to me and I was even more anxious then because I sort of then understood what was happening. . ."* Patient, page 386.<sup>30</sup> Patients also described unrealistic expectations for the intervention, believing percutaneous venting gastrostomy/gastrojejunostomy would lead to full resolution of symptoms, a return to normal eating and prolonged life expectancy.<sup>30</sup>

One study, exploring patients' and caregivers' experiences of home parenteral nutrition suggested limited understanding of the aims or process of the intervention. It was unclear whether this was due to insufficient provision of information or poor understanding of the information provided. For example, those interviewed underappreciated the complexity of home parenteral nutrition, assuming it would be simpler than they had believed: *"I thought it was probably less medical than what it is."* Companion, page 5.<sup>31</sup> However, despite the described complexities and medicalisation, patients were reluctant to stop home parenteral nutrition if it was the only intervention available to them: *"When I get to the point where I've got to say, ok, enough is enough, it won't matter then, but until that point comes then I just have to fight, keep going."* Patient, page 8.<sup>31</sup>

Overall, communication was perhaps one of the largest covered topics across the included studies. Poor communication was seen as a barrier to effective management, whereas good communication, especially between the whole care team and to the patients themselves, facilitated effective communication and therefore aided effective management and feelings of empowerment and security for patients. Some patients did have issues with information provision, including wanting more information, confusion over their management options, confusion over an intervention and what it entails, and perceived lack of involvement in the final decision for their management.

### Theme 6: Goals of care

Healthcare professionals reported the complexities of malignant bowel obstruction, however when they delivered the appropriate combination of interventions, and

the patient's symptoms were controlled, they highlighted the rewarding feeling it provided: *". . . it's just rewarding when you know that you could help somebody, and you've put things in place for them and for them to be comfortable. . ."* Nurse, page 596.<sup>27</sup> While some patients still held on to the hope that there may be a cure, most patients reported more realistic goals for themselves, such as being pain free, able to spend time with family (*"spending time with family when you get to, like, my stage, is the most important"* Patient, page 6)<sup>31</sup> and having a sense of normality: *it's just wanting to get back to normal, if you see what I mean, whatever normal is these days."* Patient, page 4.<sup>32</sup>

One study reported that as goals-of-care became complex, oncologists were more likely to involve palliative care: *"I do use palliative care a lot when I think the patient and their family and I are just not on the same page at all, because I feel like they're a good sounding board."* Gynaecologist, table 2.<sup>29</sup> However, some felt the complexities surrounding decision making and goals-of-care were too complex to involve an additional care team to the mix: *"Because of the complexity of the decision making in the malignant bowel obstruction, I don't think it's a great idea to involve another team at the moment. Especially if the patient's goals are not clear."* Gynaecologist, table 3.<sup>29</sup>

The complexity of malignant bowel obstruction meant that the decisions for care, goals and treatment options became more complex and the nature and unpredictability of the condition was also a factor in how difficult goals-of-care can be to put forward and stick to: *"You also can't predict completely how things are going to go, so that's really hard because you want to counsel them appropriately but sometimes things don't go that way. So, I think the unknown for the patient is really hard, then it makes it hard for you too."* Gynaecologist, table 4.<sup>29</sup>

Overall, goals-of-care appear to be complex and unique to each individual. However, this is hindered by the complexity of malignant bowel obstruction, its nature and unpredictable trajectory. Patients, for the most part, appeared to have realistic goals for themselves, such as being able to have the energy to meet family, have some normality to their lives and routine, and to be pain and symptom free in order to do this.

## Discussion

### Main Findings

This narrative synthesis of the qualitative literature offers confirmatory and additional information that can be used to contribute to a wider Delphi process for the development of a core outcome set to evaluate malignant bowel obstruction. Key physical symptoms that informed the Delphi process were pain/discomfort, nausea, vomiting, bloating and fatigue. Other symptoms which may be less readily considered, included distress, which was not only driven by



physical symptoms, but predominantly by psychosocial domains. These included practicalities of interventions (percutaneous venting gastrostomy/gastrojejunostomy and home parenteral nutrition), loss of social norms including eating, unpredictability of the condition and the complexities of goals of care.

The findings offer valuable insights into the patients' views and experience and identify a discordance between symptoms which are of importance to patients and those prioritised by clinicians. Even though therapeutic developments have improved survival for patients with metastatic ovarian and bowel cancer, malignant bowel obstruction remains a serious complication with no emerging new therapeutic options for two decades.<sup>42,43</sup>

Historically, studies to evaluate interventions for malignant bowel obstruction have focussed on quantitative, clinical outcomes. For example, a systematic review of the use of somatostatin analogues for the management of malignant bowel obstruction, identified six randomised control trials, each with differing primary and secondary end points.<sup>15</sup> The majority of the 45 pre-defined end points focussed on physiological parameters such as volume of gastric secretions, number of vomits per day etc. Whilst some studies relied on patient reported outcomes such as intensity of pain, only one clinical outcome captured data pertaining to quality of life; namely wellbeing.<sup>14</sup>

The heterogeneity of these study end points supports a case of need for a standardised set of outcomes, to be used in clinical practice and future research. Furthermore, without some inclusion of patients' perspectives, it will be difficult to evaluate the clinical relevance of the observations recorded. Pain, in particular, rarely featured as a clinical end point in the somatostatin randomised controlled trials, yet was the most commonly reported symptom across the qualitative studies. This correlates strongly with responses to a screening questionnaire of 37 women with advanced ovarian cancer and radiologically confirmed malignant bowel obstruction where pain, nausea, vomiting and constipation were most consistently reported.<sup>44</sup> In one of the only two published, adequately powered randomised controlled trials, the use of octreotide was associated with an increased requirement for hyoscine butyl bromide and by implication, increased pain.<sup>5</sup> With no statistical difference in the primary end point between the two groups, a greater emphasis on pain, as an outcome, might prompt a rethink about the utility of somatostatin analogues in the management of malignant bowel obstruction.

Another important finding from this review is the level of distress that is associated with a diagnosis of malignant bowel obstruction. Whilst the prognostic implications are well recognised as drivers of distress, it is clear that these worries are exacerbated when different healthcare professionals offer patients and their families mixed messages and inconsistent management plans. The challenges

of living with uncertainty are well recognised and ensuring a co-ordinated and consistent approach with malignant bowel obstruction should be considered a minimum standard of care.

### *Strengths and weaknesses*

It is appropriate to recognise the limitations of this review. Of the nine papers reviewed, three focussed on patient experience of symptoms, with the remainder reporting on experiences of parenteral nutrition, venting procedures, clinical decision making and a self-care tool. The review was limited by the timepoint of 10 years, therefore it is possible earlier papers may have been missed. However, we conducted a scoping search, which highlighted the scarcity of qualitative evidence before 2010, which has been further reinforced by the lack of qualitative studies referenced in the included studies' reference lists, which were hand searched. The one exception was the Gwilliam paper,<sup>28</sup> which was referenced in some of the included studies, so it was decided the paper was to be included in the review due to it being the only qualitative paper referenced specific to malignant bowel obstruction pre-2010. Most importantly, the limited number of relevant qualitative studies illustrates how little the patient voice has been recognised in the evaluation and management of malignant bowel obstruction.

### *What this study adds*

These qualitative data shall contribute to informing the wider study to develop a core outcome set for malignant bowel obstruction, which shall hopefully ensure future studies in the field adopt a standardised system of evaluating and reporting.<sup>19</sup> However, the under representation of patient experience in malignant bowel obstruction studies is of concern and should be addressed as a matter of urgency.

### **Acknowledgements**

This work was supported by Marie Curie core funding of Professors Simon Noble and Annmarie Nelson's personal chairs. Professor Fliss Murtagh is a National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.

### **Author contributions**

SN, JWB, MJ, FM, DC, GO, EGB, AN and KS were involved in the conception of the study. ALL authors contributed to protocol development. EB, MM and AB led on data collection, analyses, and writing. SN and AN provided supervision and oversight of data collection, analyses, writing and provided adjudication over study inclusion. MJ, FM, DC, GO, EB, AO, KS and JWB provided substantial contribution to the study

analyses and writing. All authors read and approved the final manuscript.

### Data management and sharing

The data is readily available in supplementary files/appendices.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Marie Curie Research Grants Scheme [grant number MCRGS-20171220-802].

### Research ethics and patient consent

The review did not directly involve human participants and therefore required no approval from an ethics committee, however the overarching study that this review is a part of, was reviewed by the Wales Research Ethics Committee 5 (Wales REC 5) on 10th December 2019 (Ref 19/WA/0340).

### ORCID iDs

Elin Baddeley  <https://orcid.org/0000-0002-7571-4820>

Mala Mann  <https://orcid.org/0000-0002-2554-9265>

Miriam J Johnson  <https://orcid.org/0000-0001-6204-9158>

David Currow  <https://orcid.org/0000-0003-1988-1250>

Fliiss E M Murtagh  <https://orcid.org/0000-0003-1289-3726>

Jason W Boland  <https://orcid.org/0000-0001-5272-3057>

### Supplemental material

Supplemental material for this article is available online.

### References

1. Tuca A, Guell E, Martinez-Losada E, et al. Malignant bowel obstruction in advanced cancer patients: epidemiology, management, and factors influencing spontaneous resolution. *Cancer Manag Res* 2012; 4: 159–169.
2. Mercadante S. Intestinal dysfunction and obstruction. In: Walsh D (ed.) *Palliative medicine*. 1st ed. Philadelphia, PA: Saunders/ Elsevier, 2009, pp.1267–1275.
3. Boland JW and Boland EG. Malignant bowel obstruction. In: Cherny NI, Fallon MT, Kaasa S, et al. (eds) *Oxford textbook of palliative medicine*. 6th ed. Oxford: Oxford University Press, 2021, pp. 904–917.
4. Gemlo B, Rayner AA, Lewis B, et al. Home support of patients with end-stage malignant bowel obstruction using hydration and venting gastrostomy. *Am J Surg* 1986; 152(1): 100–104.
5. Currow DC, Quinn S, Agar M, et al. Double-blind, placebo-controlled, randomized trial of octreotide in malignant bowel obstruction. *J Pain Symptom Manage* 2015; 49(5): 814–821.
6. Peng X, Wang P, Li S, et al. Randomized clinical trial comparing octreotide and scopolamine butylbromide in symptom control of patients with inoperable bowel obstruction due to advanced ovarian cancer. *World J Surg Oncol* 2015; 13: 50.
7. Kubota H, Taguchi K, Kobayashi D, et al. Clinical impact of palliative treatment using octreotide for inoperable malignant bowel obstruction caused by advanced urological cancer. *Asian Pac J Cancer Prev* 2013; 14(12): 7107–7110.
8. Zhang Y, Gao Y, Ma Q, et al. Randomised clinical trial investigating the effects of combined administration of octreotide and methylglucamine diatrizoate in the older persons with adhesive small bowel obstruction. *Dig Liver Dis* 2006; 38(3): 188–194.
9. Khoo D, Hall E, Motson R, et al. Palliation of malignant intestinal obstruction using octreotide. *Eur J Cancer* 1994; 30A(1): 28–30.
10. Selby D, Wright F, Stilos K, et al. Room for improvement? A quality-of-life assessment in patients with malignant bowel obstruction. *Palliat Med* 2010; 24(1): 38–45.
11. Jayson GC, Kohn EC, Kitchener HC, et al. Ovarian cancer. *Lancet* 2014; 384(9951): 1376–1388.
12. Laval G, Marcelin-Benazech B, Guirimand F, et al. Recommendations for bowel obstruction with peritoneal carcinomatosis. *J Pain Symptom Manage* 2014; 48(1): 75–91.
13. Guidelines SPC. Bowel Obstruction. 27 April 2020 (updated); 13 November 2013 (created) [Palliative Care Guidelines for Bowel obstruction], <https://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control/bowel-obstruction.aspx> (accessed 17 September 2021).
14. Mariani P, Blumberg J, Landau A, et al. Symptomatic treatment with lanreotide microparticles in inoperable bowel obstruction resulting from peritoneal carcinomatosis: a randomized, double-blind, placebo-controlled phase III study. *J Clin Oncol* 2012; 30(35): 4337–4343.
15. Obita GP, Boland EG, Currow DC, et al. Somatostatin analogues compared with placebo and other pharmacologic agents in the management of symptoms of inoperable malignant bowel obstruction: a systematic review. *J Pain Symptom Manage* 2016; 52(6): 901–919.e1.
16. Walsh D, Davis M, Ripamonti C, et al. 2016 Updated MASCC/ESMO consensus recommendations: management of nausea and vomiting in advanced cancer. *Support Care Cancer* 2017; 25(1): 333–340.
17. Mercadante S. Octreotide for malignant bowel obstruction: commentary on Currow et al. *J Pain Symptom Manage* 2015; 49(5): 813.
18. Johnson MJ and Noble SIR. Challenging previously held beliefs about clinical practice: evidence or experience? *J Pain Symptom Manage* 2015; 50(1): e1–e2.
19. Baddeley E, Bravington A, Johnson M, et al. Development of a core outcome set to use in the research and assessment of malignant bowel obstruction: protocol for the RAMBO study. *BMJ Open* 2020; 10: e039154.
20. COMET Initiative. Research Assessment outcome measures for Malignant Bowel Obstruction (RAMBO Study), <https://www.comet-initiative.org/Studies/Details/1402> (2019, accessed 17 September 2021).
21. Mann M, Woodward A, Nelson A, et al. Palliative Care Evidence Review Service (PaCERS): a knowledge transfer partnership. *Health Res Policy Syst* 2019; 17(1): 100.

22. International Prospective Register of Systematic Reviews (PROSPERO). Symptom burden and lived experiences of patients, companions and health care professionals on the management of malignant bowel obstruction (MBO): a rapid review, [https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=176393](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=176393) (2020, accessed 13 July 2021).
23. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021; 372: n71.
24. Specialist Unit for Review Evidence (SURE). Questions to assist with the critical appraisal of qualitative studies, <https://www.cardiff.ac.uk/specialist-unit-for-review-evidence/resources/critical-appraisal-checklists> (2018, accessed 12 July 2021).
25. Popay J, Roberts H, Sowden A, et al. *Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme*. Version 1. Microsoft Word - NS synthesis guidance Version 1 April formatted 2006.doc (lancaster.ac.uk) (2006, accessed 24 February 2022).
26. Cusimano MC, Sajewycz K, Nelson M, et al. Supported self-management as a model for end-of-life care in the setting of malignant bowel obstruction: a qualitative study. *Gynecol Oncol* 2020; 157(3): 745–753.
27. Daines P, Stilos K, Moura S, et al. Nurses' experiences caring for patients and families dealing with malignant bowel obstruction. *Int J Palliat Nurs* 2013; 19(12): 593–598.
28. Gwilliam B and Bailey C. The nature of terminal malignant bowel obstruction and its impact on patients with advanced cancer. *Int J Palliat Nurs* 2001; 7(10): 474–481.
29. Hoppenot C, Hlubocky FJ, Chor J, et al. Approach to palliative care consultation for patients with malignant bowel obstruction in gynecologic oncology: a qualitative analysis of physician perspectives. *JCO Oncol Pract* 2020; 16(8): 483–489.
30. Singh Curry R, Evans E, Raftery AM, et al. Percutaneous venting gastrostomy/gastrojejunostomy for malignant bowel obstruction: a qualitative study. *BMJ Support Palliat Care* 2019; 9(4): 381–388.
31. Sowerbutts AM, Lal S, Sremanakova J, et al. Palliative home parenteral nutrition in patients with ovarian cancer and malignant bowel obstruction: experiences of women and family caregivers. *BMC Palliat Care* 2019; 18(1): 120.
32. Sowerbutts AM, Lal S, Sremanakova J, et al. Dealing with loss: food and eating in women with ovarian cancer on parenteral nutrition. *J Hum Nutr Diet* 2020; 33(4): 550–556.
33. Sowerbutts AM, Lal S, Sremanakova J, et al. Discharging women with advanced ovarian cancer on home parenteral nutrition: making and implementing the decision. *Nutrients* 2020; 12(1): 166.
34. Williams LA, Bruera E and Badgwell B. In search of the optimal outcome measure for patients with advanced cancer and gastrointestinal obstruction: a qualitative research study. *Ann Surg Oncol* 2020; 27(8): 2646–2652.
35. Astara G, Lai E, Tolu S, et al. Medical management of malignant bowel obstruction: our center experience. *Ann Oncol* 2017; 28(Suppl. 6): vi15.
36. Brooksbank MA, Game PA, Ashby MA, et al. Palliative venting gastrostomy in malignant intestinal obstruction. *Palliat Med* 2002; 16(6): 520–526.
37. LeBlanc JF, Martel M and Barkun AN. Examination of physicians' perception of the indications of colorectal stents in the management of malignant large bowel obstruction: a provincial survey. *Can J Gastroenterol Hepatol* 2016; 2016: 4629710.
38. McCaffrey N, Asser T, Fazekas B, et al. Does octreotide improve HrQOL in patients with malignant bowel obstruction? Palliative Care Australia (PCA), Search Literature - Grey Literature - Finding Evidence - Evidence (caresearch.com.au), 2017.
39. Santarpia L and Bozzetti F. Acute impact of home parenteral nutrition in patients with late-stage cancer on family caregivers: preliminary data. *Support Care Cancer* 2018; 26(2): 667–671.
40. To T, Agar M, Rowett D, et al. Prescribing preferences for malignant bowel obstruction in palliative medicine. In: *Biennial conference (ANZSPM) 2012*, ANZSPM, Search Literature - Grey Literature - Finding Evidence - Evidence (caresearch.com.au), 2012.
41. Kuo HJ, Jhang SY and Shun SC. Using the FOCUS family intervention in caring for a patient-spouse dyad with advanced colorectal cancer. *Hu Li Za Zhi* 2017; 64(3): 98–104.
42. Torre LA, Trabert B, DeSantis CE, et al. Ovarian cancer statistics, 2018. *CA Cancer J Clin* 2018; 68(4): 284–296.
43. Brouwer NPM, Bos A, Lemmens V, et al. An overview of 25 years of incidence, treatment and outcome of colorectal cancer patients. *Int J Cancer* 2018; 143(11): 2758–2766.
44. Morgan RD, Stamatopoulou S, Mescallado N, et al. Screening tool for malignant bowel obstruction in relapsed, metastatic ovarian cancer. *ESMO Open* 2019; 4: e000463.