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Inoperable malignant bowel obstruction: palliative interventions outcomes – mixed-methods systematic review

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ABSTRACT

Background Parenteral nutrition (PN) and palliative venting gastrostomies (PVG) are two interventions used clinically to manage inoperable malignant bowel obstruction (MBO); however, little is known about their role in clinical and quality-of-life outcomes to inform clinical decision making.

Aim To examine the impact of PN and PVG on clinical and quality-of-life outcomes in inoperable MBO.

Design A mixed-methods systematic review and narrative synthesis.

Data sources The following databases were searched (from inception to 29 April 2021): MEDLINE, Embase, Cochrane Central Register of Controlled Trials, Web of Science, CINAHL, Bielefeld Academic Search Engine, Health Technology Assessment and CareSearch for qualitative or quantitative studies of MBO, and PN or PVG. Titles, abstracts and papers were independently screened and quality appraised.

Results A total of 47 studies representing 3538 participants were included. Current evidence cannot tell us whether these interventions improve MBO survival, but this was a firm belief by patients and clinicians informing their decision. Both interventions appear to allow patients valuable time at home. PVG provides relief from nausea and vomiting. Both interventions improve quality of life but not without significant burdens. Nutritional and performance status may be maintained or improved with PN.

Conclusion PN and PVG seem to allow valuable time at home. We found no conclusive evidence to show either intervention prolonged survival, due to the lack of randomised controlled trials that have to date not been performed due to concerns about equipoise. Well-designed studies regarding survival for both interventions are needed.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Clinical decision making in malignant bowel obstruction is complex, with a range of options available to the clinician.
⇒ There are currently no national agreed guidelines to inform clinical decision making regarding malignant bowel obstruction management.

WHAT THIS STUDY ADDS

⇒ Gastrostomy appears to be an effective intervention providing symptoms relief for patients with malignant bowel obstruction, allowing patients to spend time out of hospital and appears to improve quality of life for most.
⇒ Parenteral nutrition plays a vital role in managing malignant bowel obstruction, allowing patients valuable time at home, and appears to improve quality of life for most but with associated burdens.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE AND/OR POLICY

⇒ Parenteral nutrition and gastrostomy seem to support patients' valuable time at home.
⇒ Given the burdens associated with both interventions, healthcare professionals must present an honest and realistic account of the benefits and challenges of the treatment options.

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INTRODUCTION

Malignant bowel obstruction (MBO) is a serious complication of cancer, affecting an estimated 3%–15% of patients with cancer globally,[1] and most common with primary cancers of gynaecological and gastrointestinal origin (50% and 28%,

respectively).[1] People with MBO describe distressing abdominal pain and distension, nausea and vomiting, inability to eat and drink with a consequential reduction in quality of life (QoL), nutritional and performance status.[2–5]

Surgery provides the best option for longer-term survival.[6–8] However, surgery is often contraindicated due to ascites, peritoneal carcinomatosis, multiple sites of obstruction, and poor functional and nutritional status.[6] Those with inoperable MBO (IMBO) are managed medically[9] with analgesics, corticosteroids, antiemetics and antisecretory agents. Those with IMBO may also be managed with parenteral nutrition (PN), gut decompression (eg, palliative venting gastrostomy (PVG), nasogastric tube drainage) or stenting.[2 10] Clinical decision making is challenging, with only low-level evidence to guide clinicians in day-to-day decision making with no nationally agreed recommendations leading to wide variation between clinical centres.[6 11 12] Management choices are typically based on clinicians' individual clinical experience or patients' goals (if explored).[6]

The use of PN in advanced cancer is receiving growing attention with the publication of systematic reviews[13–16]; two focused on MBO solely,[13 15] two focused on advanced cancer, however, most included papers had a large proportion of participants with MBO.[14 16] These reviews focused mostly on survival and rarely evaluated other important outcomes such as QoL and health resource utilisation.

There is only one systematic review exploring the use of PVG for MBO with regard to safety and efficacy for symptom relief[17] but again, this did not address impact on QoL or health service utilisation.

We aim to synthesise systematically the current evidence on the use of PVG and PN in MBO, investigating how they affect: survival, health-related QoL, symptoms, health service utilisation, physical function and nutritional status. We included PVG for gut decompression or treatment with PN as destination treatment, with a comparator (if available) of no decompressive support or no PN support.

METHODS

The study is reported per the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[18]

Search strategy

The following databases were searched (from database inception to 2 March 2020): MEDLINE and Embase via OVID, CENTRAL via The Cochrane Library, Web of Science Core Collection, CINAHL Complete via EBSCOhost, Bielefeld Academic Search Engine (BASE) and CareSearch (see online supplemental file 1) for qualitative or quantitative studies of MBO, and PN and/or PVG, with no language limits.

Table 1 Inclusion and exclusion criteria for identifying relevant studies via search strategies

Inclusion criteria	Exclusion criteria
PN	
People over 16 years of age with inoperable MBO. Receiving PN via a central venous catheter as destination palliative treatment.	Treatment with curative intent. Receiving PN through a peripheral vein. Receiving only intravenous fluids. Receiving enteral feeding alongside PN not deemed for quality of life. Patients were <16 years old. PN was administered preoperatively, perioperatively or postoperatively to assess complications related to surgery.
PVG	
People over 16 years of age with inoperable MBO. Receiving gut decompression via a PVG tube or nasogastric tube as destination palliative treatment. Studies that include patients with both benign and malignant diseases if the results were reported separately for each group.	Treatment with curative intent. Patients were <16 years old. PVG insertion for decompression in non-malignant disease.

MBO, malignant bowel obstruction; PN, parenteral nutrition; PVG, palliative venting gastrostomies.

We searched for any currently recruiting trials in ClinicalTrials.gov (http://clinicaltrials.gov/), EU Clinical Trials Register (https://www.clinicaltrialsregister.eu/) and in the WHO International Clinical Trials Registry Platform (ICTRP) search portal (http://apps.who.int/trialsearch/).

The search was updated on 29 April 2021 using the search and screening strategy fully outlined in this paper from the 2 March 2020 to the 29 April 2021. The numbers of articles retrieved from each database and the two searches can be seen in online supplemental file 1.

Forward and backward citation searching of all included studies and relevant systematic reviews was completed: we examined the reference lists of included studies and identified articles citing included studies in Web of Science.

Inclusion and exclusion criteria

Study eligibility criteria are detailed in table 1.

Study selection

All titles and abstracts retrieved by electronic searching were downloaded to an Endnote 20 library, and duplicates removed according to a published protocol.[19] The remaining articles were uploaded to the online citation-screening tool Covidence.[20] Studies were dual screened independently (MP, YM) based on title and abstract for eligibility. Full-text articles were also retrieved in the case of uncertainty. Full texts were reviewed by two authors (MP, YM, AB and JC). Any disagreements were resolved through consensus.

Data extraction

Data were extracted using a piloted and modified bespoke form. MP extracted data from all studies, and YM and AB each from a random 25%.

Quality assessment

Randomised controlled trials (RCTs) were assessed against the Risk of Bias 2.0 tool.[21] All cohort studies were appraised against the Critical Appraisal Skills Programme cohort checklist tool[22] items 1–10. All qualitative studies were evaluated against the Critical Appraisal Skills Programme qualitative checklist tool[23] items 1–10 (see online supplemental file 2).

Analysis

The Joanna Briggs Institute convergent segregated approach to synthesis and integration was followed; this consists of conducting separate quantitative synthesis and qualitative synthesis, followed by integrating evidence derived from both.[24]

For the qualitative synthesis, the direct quotation data were synthesised by MP and AB using thematic synthesis.[25 26] This allowed the context of each study to be considered while aiming to produce a generalisable synthesis.[25] Participant quotes and the authors' interpretations were used. The below analysis was conducted on paper with the final analysis broken down into quotes, codes, subthemes and themes (online supplemental file 3). Three stages were conducted: (1) initial data coded regarding experiences of PN and PVG (MP, AB); (2) descriptive themes generated, with codes grouped into categories (MP, AB) and (3) analytical themes generated both inductively and deductively, with the investigators (AB, MP) generating themes independently, then through discussion with a third investigator (MJJ). A decision was made to combine the findings from the PN and PVG literature as the themes arising were common throughout.

For the quantitative synthesis, due to significant heterogeneity, a narrative summary only was completed.

RESULTS

The search returned 5673 unique articles after deduplication. From this, 47 studies, representing 3538 participants, including 30 participants from four qualitative studies, published between 1992 and 2021, were included (see PRISMA flow chart, figure 1)[18]

Study characteristics: quantitative

Online supplemental file 4 provides summary descriptions of the included quantitative studies. There were 6 prospective,[27–32] 35 retrospective cohort studies,[7 8 33–67] 1 mixed-method study[68] and 2 RCTs.[69 70] Sample sizes ranged from 7 to 629. Studies were globally represented; 1 study from Australasia,[50] 5 from Asia,[31 40 60 69 70] 17 from Europe[27–30 32 35 39 42 44–47 54 64 67 68] and 21 from North America.[7 8 33 34 36–38 43 49 52 53 55–59 61–63 65 66]

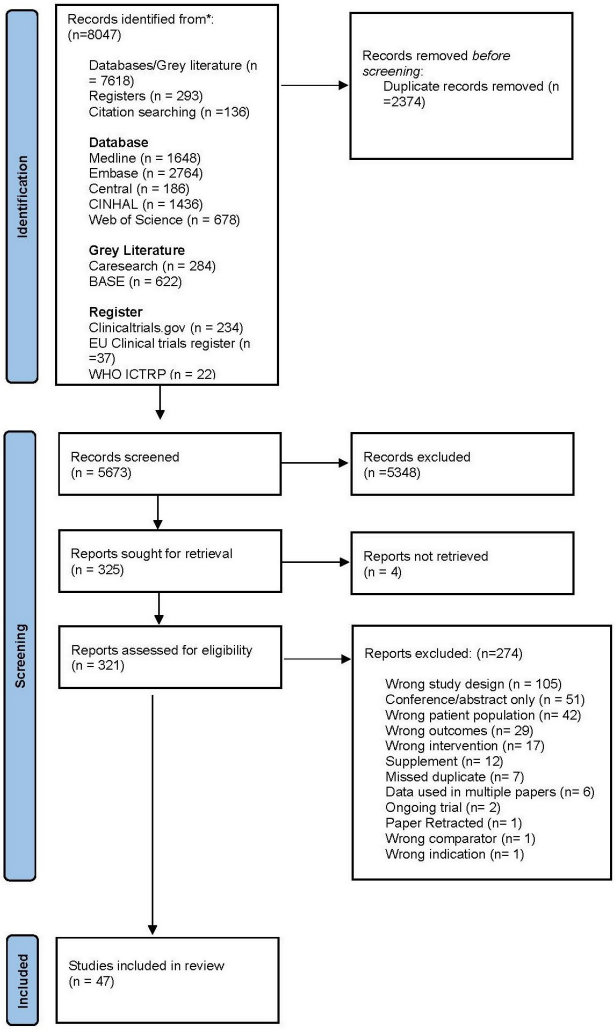

Figure 1 Identification of studies via databases and registers.

Parenteral nutrition

Participants

Twenty-one studies were included, with 1884 participants (age ranged from 22 to 88 years; females 61%). The underlying primary malignancy was the gastrointestinal tract in just over half (53%) of patients, gynaecological in a quarter (24%) of patients (accounting for the female predominance) and other sites in a further quarter (26%). MBO was reported in 100% of patients in 14 studies[29 33–35 37–40 44 45 47 68 70] and between 72% and 90% in the other 7 studies[30–32 42 43 46 48]; overall, 94% of included patients (see online supplemental file 3).

Survival

All PN studies reported on overall survival. However, the definition of length of survival was inconsistent, with seven definitions for survival given, with no definition in one study,[31] reflecting different study

populations (see online supplemental file 4). The possibility of combining quantitative data for a meta-analysis regarding survival was explored, but due to significant heterogeneity, a narrative summary only was completed.[71]

Seventeen studies reported median survivals ranging between 13 and 143 days (range: 2–2111 days).[29–34 36–39 42 43 45–47 68 70] Seven studies reported mean survivals between 30 and 198 days (range: for 1–1715 days).[35 40 40 41 44 44 48]

One retrospective cohort study found that those receiving PN in addition to anticancer treatment (chemotherapy) had a longer median survival (89 vs 71 days, (p=0.031)).[33] A prospective[32] and another retrospective cohort study[39] found that those receiving PN in addition to anticancer treatment had longer 3-month and 6-month survivals (p<0.00001.[39]

Only two retrospective cohort studies compared survival in those receiving PN compared with those who did not as a sole intervention. Those receiving PN lived longer (323 vs 91 days, p=0.0021[45]; 72 vs 41 days, p=0.01.[36] Though for one study[45] this improved survival compared those who received PN to those who did not despite being assessed retrospectively as eligible by the study team.

Two retrospective cohort studies[42 48] and one prospective cohort study[31] showed a positive association between performance status and survival; a Karnofsky performance status >50 at baseline was associated with longer survival.

A further retrospective cohort study[39] found similar results using the Eastern Cooperative Oncology Group performance status, rated from 0, fully active, to 5, dead. They found baseline performance status impacted on survival (0=median 680 (range 543–1393); 1=median 174 (65–748); 2=median 61.5 (25–399); 3=median 26 (16–64) days).

Health-related QoL

A prospective cohort study[32] found an improvement over 3 months for global QoL, physical, role and emotional functioning, as well as appetite loss and fatigue. An additional retrospective cohort study[30] reported physical, psychological, and activity assessments; roughly half deteriorated and 40% improved—with a small percentage showing no change using the Rotterdam symptom checklist. In contrast, only a quarter of patients showed a worsening of the well-being assessment.

A retrospective cohort study[43] used non-validated measures but saw a statistically significant improvement in gastrointestinal discomfort, nausea, vomiting, fatigue level, morale and social interactions during home PN use as compared with prehome PN status (p=0.05). Those with a prehome PN and Karnofsky >40 had greater improvement in QoL than those with worse performance status (see online supplemental file 3).

Performance status

Only three studies reported the impact of PN on performance status (table 2). A prospective cohort study[30]

Table 2 Parenteral nutrition and performance status

Study	Performance status metric	Numbers performance status measured	Time point	Score
Bozzetti *et al*[30] 2002	KPS	69	Baseline	Median 60
		69	'Until 3 months prior to death'	'stable'
King *et al*[43] 1993	KPS	72	Baseline	48
		72	'During home parenteral nutrition'	47
Santarpia *et al*[47] 2006	KPS	In 64 patients who survived longer than 60 days		Mean
		64	Baseline	≤40 12 ≥50 52
		64	1 month	≤40 10 ≥50 54
		In 39 patients who survived longer than 90 days		Mean
		39	Baseline	≤40 5 ≥50 34
		39	1 month	≤40 4 ≥50 35
Ruggeri *et al*[46] 2020	Karnofsky Performance Status Scale	Precachexia		Mean
		249	Baseline	56
		249	1 month	58
		Cachexia		Mean
		478	Baseline	52
		478	1 month	53
		Refractory cachexia		Mean
		242	Baseline	49
		242	1 month	49

Table 3 Parenteral nutrition (PN) and nutritional status

Study	Numbers performance status measured	Time point	Weight (kg)	
Bozzetti *et al*[30] 2002	69	Baseline	Median- 52.5 (range 35.5–77.5)	
	69	Time of death	Median 54.0 (range 36–78)	
Keane *et al*[42] 2018	71	Starting PN	55.3±12.3	
	37	Outpatient clinic 0–3 months	54.5±9	
	19	Outpatient clinic 3–6 months	58.6±11.3	
King *et al*[43] 1993	61	Pre-home parenteral nutrition	Mean (±SD) 54.5±13.7	
	55	1 week	Mean (±SD) 56.4±12.8	
	50	1 month	Mean (±SD) 57.2±12.4	
	18	3 months	Mean (±SD) 57.7±11.2	
	9	6 months	Mean (±SD) 59.8±11.7	
	7	1 year	Mean (±SD) 57.4±8.3	
Patel[45 77]			Referred for PN	Not referred for PN
	105	At obstructive episode	Median (range) 53.9 (41.8–89) n=47	Median (range) 57 (38-100) n=58
	60	At 0–3 months follow-up	Median (range) 54 (39.9–82.8) n=31	Median (range) 55.0 (41.8–89) n=29
	39	At 4–6 months follow-up	Median (range) 55.7 (38.7–85.4) n=22	Median (range) 55.8 (41.8–89) n=17
Santarpia *et al*[47] 2006		In 64 patients who survived longer than 60 days		
	64	Baseline	Mean (±SD) 51.7±10.3	
	64	1 month	Mean (±SD) 53.2±10.3	
		In 39 patients who survived longer than 90 days		
	39	Baseline	Mean (±SD) 50.5±10.2	
	39	1 month	Mean (±SD) 52.0±10.1	

and a retrospective cohort study[43] found performance status was maintained. A further retrospective cohort study found an improvement (most marked in those living longer).[47] However, patients with a KPS <30 were excluded from these studies.

Nutritional status

One prospective cohort study[30] reported home PN maintained the same nutritional status assessed at the start of treatment until death. Four retrospective cohort studies[42 43 45 47] found an improvement in body weight of those on home PN (improvement greater in those living longer). Interestingly, one[45] found the opposite was true; those who were not referred for PN had decreases in weight over time. Findings summarised in table 3.

Symptoms

No studies reported on symptoms unless reported in QoL data.

Health service utilisation

The available health service utilisation data came from seven retrospective cohort studies (online supplemental file 5).[34 35 37–39 43 45]

Readmission rates were variable with low medians between 0 and 2 but a wide range of 0–13[37 39 43 45] Reasons for readmissions were limited and time frames were lacking. One study[43] reported 11/124 (9%) hospitalisations were for home PN-related complications, the others being for cancer therapy or disease complications. Two further studies reported on readmissions, one[38] reporting 1/9 (11%) had five readmissions. The second[34] reported 3/18 (17%) were readmitted to evaluate possible home PN-related complications.

Intensive care unit (ICU) admissions were reported in two studies and varied widely (from a median of 0[45] to 23/82 (28.1%)[37]).

Median length of stay ranged from 10.1 to 26.5 days.[35 37 45] With one[45] study reporting a greater length of stay in those referred for PN than those who were not (28 vs 9 days, p=0.0001).

Place of death

Three retrospective cohort studies reported on place of death (online supplemental file 5).[36 42 45] Most patients died in their home or hospice (range 68%–81.3%) reported across the three studies.

Palliative venting gastrostomy

Participants

Twenty-three studies were included for quantitative analysis, with 1657 participants (age ranged from 20 to 95 years; females 78%) (online supplemental file 4). The underlying primary malignancy was gynaecological in 57% of patients (accounting for the female predominance), the gastrointestinal tract in 37% of patients and other sites in 6%. All participants in all studies had MBO.

Survival

All studies reported the overall survival of participants with PVG, again, defining survival from different points, or not defined in one[8] (see online supplemental file 4). Survival was however heavily confounded by the varying use of PN post-PVG.

Thirteen studies reported median survivals between 13 and 63 days, range from 1 to 1226 days.[7 27 49 50 53 54 56 59–63 67] Five studies reported mean survivals between 53 and 135 days, range from 5 to 2772 days.[28 52 57 58 65] Two studies reported 'average survival' between 83.7 and 147 days, range 20–364 days.[64 66]

One study reported percentage alive at 30 days, 1 year and 3 years, of 54.8%, 11.43% and 9.5%, respectively.[55] One study stated survival of 50 days for the PVG group and 86 days for the nasogastric tube group without further qualification of the measure.[69]

Quality of life

An RCT[69] found higher QoL scores for PVG versus nasogastric tube for both EuroQl-5D (mean—7.132 (4.543–9.702) vs 3.663 (0.464–6.862)) and Short-Form-8 scores (mean—420.1 (282.6–557.6) vs 199.4 (22.2–376.6)).

A retrospective cohort study[67] had 25 completed symptoms Distress Scale scores. Sixteen (64 %) improved (41 vs 32.6, pre-PVG and post-PVG median scores, respectively, $p \leq 0.01$), two (8 %) showed the same scores as at baseline, and seven (28 %) had non-significant worsening (30.85 vs 36.14, $p=0.18$) of QoL (see online supplemental file 4).

Performance status

No studies reported on performance status.

Nutritional status

No studies reported on nutritional status.

Symptoms

Two prospective cohort[27 28] and thirteen retrospective cohort studies[49 50 52 57–60 62–67] reported a reduction in nausea and vomiting in 657/750 (88%) participants. A further retrospective study showed that PVG significantly reduced the daily frequency of vomiting to 18% of the initial value, and a reduced probability of nausea to 50% (both $p<0.001$).[54]

One prospective cohort[28] and seven retrospective cohort studies[57 59 62–65 67] reported whether participants were able to resume an oral diet, either liquid or soft diet, following insertion of PVG. Where noted, ability to tolerate some sort of diet was achieved in 353/432 (82%). A retrospective cohort study[50] reported the ability to resume some oral intake was usually viewed by patients and families positively (see online supplemental file 3).

Health service utilisation

See online supplemental file 5

Hospital readmission rates varied from 11/96 (11.4%)[58] to 4/7 (47%).[65] Reasons for readmission were reported; PVG-related events between 4/96 (4%)[58] and 48/115 (42%),[53] recurrent 'average' length of time spent at home prior to readmission was 21.7 days (range 5–60 days)[59] to 126 days (range 7–467 days).[65]

Median length of stay varied from 6 to 23 days (range 1–60). An additional retrospective cohort study reported median length of stay prior to placement of PVG of 6 days (range 1–27).[64]

Twenty/51 (39%)[50] to 83% (20/24)[64] of patients with PVG were discharged home. Hospice enrolment rates varied from 5/53 (9.4%)[63] to 95/117 (81%).[56] A further retrospective cohort study[67] reported 116/158) (81.6% of patients discharged, though discharge location unknown).

The largest study[7] included in the review was a retrospective cohort study of 3583 people. They found PVG use was associated with lower intensity hospital service utilisation (higher hospice enrolment, fewer readmissions, ICU admissions and hospital deaths) at the end of life, compared with medical management or surgery to manage MBO. While this was a retrospective cohort study the authors used regression models to adjust for patient and hospital covariates to account for confounders.

Place of death

Death in hospital was wide ranging from 2/53 (4%) to 4/7 (57%).[65] There were few data about death outside of hospital (online supplemental file 5). Of the data available proportions of those dying at home ranged from 6/51 (12%)[50] to 3/7 (43%).[65] Another retrospective cohort study[62] reported on home or hospice care with 75 of 88 (85%) patients dying at home or under hospice care. Unfortunately for most studies the place of death for most patients is unknown.

A retrospective cohort study[54] reported deaths for their full cohort: hospital n=46 (61%), home n=23 (30%), and inpatient hospice n=6 (9%). A further study[54] reported discharge disposition of their full cohort, presumed to be place of death:

home n=22 (40%), rehabilitation n=7 (15%) and hospice n=25 (45%).

Quality of included studies

The general quality of the observational studies was poor, with the majority being retrospective studies without a comparator (see online supplemental file 2). The studies did not sufficiently address confounding variables, such as performance status, and biases such as no randomisation to treatment groups, and no blinding of participants or healthcare professionals. Likewise, the risk of bias in the RCTs was high and none compared either PN or PVG with usual care alone. The quality of the qualitative studies was of higher quality, though generalisability was inherently limited by its narrow focus; this not being an aim of qualitative research.

QUALITATIVE SYNTHESIS

Parenteral nutrition

Three studies[68 72 73] were included; all reported findings from 57 interviews from the same study group: 20 women with ovarian cancer, mean age 67 (±SD 7.5), and 13 family caregivers.

Palliative venting gastrostomies

One study[74] was included. The study included 11 participants (10/11 women; 7 with gynaecological cancer and 4 with colorectal cancer). Twelve interviews were conducted: 11 initial face-to-face interviews and 1 telephone reinterview.

Interview findings

All quotes are from patients unless otherwise highlighted and are shown in online supplemental file 3.

Two key themes emerged: (1) A stark decision: do or die; (2) Hope versus reality of the intervention.

A stark decision: do or die

Patients and carers felt there was no good alternative to PN. They viewed the choice as between life (PN) or death (starve).

> It's either die with food or (home PN) for the rest of your days and I'd sooner live and be on (PN)[68]
> Well, to me it was a no option thing. I don't think they could have done anything else, bar starve me… if that's what's keeping me alive, it's what I have to have isn't it. So I don't think (there was) a decision as such, if there was no other… if I can't eat, it will be next best thing(PN)[74]

Whether this belief was a result of over-optimistic emphasis from clinicians on possible survival benefits (given the lack of level 1a evidence regarding survival) or received in this manner because of the serious nature of the situation was not clear. Whichever, with such stark alternatives, most were trusting of their clinical team and felt they had little choice but to agree with a decision already made.

> Certainly yes, I mean what's the alternative…you just have to go with what the doctors recommend, I think. (PVG)[74]

Hopes versus realities of the intervention

The interventions themselves brought benefits in perceived quantity and QoL; a view held by both patients and carers.

> Spending time with family when you get to, like, my stage, is the most important for everybody (PN)[68]
> It's keeping her alive really. That's the big advantage. (Husband). (PN)[68]

For some the benefits were the control of symptoms or improved function.

> Well they explained that 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. (PVG)[74]
> it's given me, yes, more energy (PN)[68]

However, both interventions brought their own burdens. For both the patients and the carers these burdens were more than they had expected.

> initially when this was being discussed with us … I thought it was probably less medical than what it is (Daughter). (PN)[68]
> It wasn't as easy as it was made out to be" (PN)[68]

This underestimation of the impact included the procedures involved, especially if written information was not given prior to the intervention.

> when I got down to radiology, Dr X (Consultant IR) came and explained it all to me and I was even more anxious then because I sort of then understood what was happening… (PVG)[74]

The physical burden of the intervention on both patient and carer was considerable, with many participants managing both PN and PVG together.

> (are you able to walk up and down the stairs?) … not when carrying my bags (referring to her PVG, PN and syringe pump), but X (partner) carries those either behind or in front of me. (PN)[68]
> My husband has been in a lot of discomfort, it has been leaking all the time, he's being changed numerous times a day, the beds have to be changed and now his skin is all sore. (PVG)[74]

Alongside the physical burden, an emotional burden was expressed by patients, which was often echoed by carers.

> It would be wonderful if I could have even 5 hours sleep without a break (PN)[68]
> You can smell it though, even if it's not leaking. I feel like…it smells like sewage, it's not faecal, it's worse than that, it's a sewage smell and I feel like I can smell it all the time and anyone who is anywhere near me can smell it. It is making me quite paranoid; I am constantly asking my husband if he can smell

> it…I don't get embarrassed too easily, but I do find that quite difficult to deal with) (PVG)[74]

The emotional burden was apparent, particularly when the duration of care went on, and hypervigilance and sleeplessness aggravating the distress.

> I'm awake most of the night listening for her, but she tells me not to help her(Husband) (PN)[68]"
> What you sign on for when you get married (Husband) (at the end of the second interview, he reported feeling like a 'prisoner') (PN)[68]

Although stoicism and resilience and adaptation by many to a new normal was apparent, the sense of what had been lost was felt keenly.

> when I go in the shower and everything, I can … take both tubes off, and I'm a different person (PN)[68]
> It just becomes a way of life really, you know what I mean, this is how your day goes and this is what it is. A nurse comes and takes it off in a morning and then a nurse comes at night and puts it back on (PN)[68]

INTEGRATION OF QUANTITATIVE AND QUALITATIVE EVIDENCE

Each outcome of interest was determined to be in concordance, dissonance or silent from the quantitative evidence or qualitative studies using the convergent segregated approach to synthesis and integration.[24] This methodology allows exploration of the results of findings from the quantitative and qualitative synthesis to examine if there is agreement (concordance), disagreement (dissonance), or have no relationship or not mentioned (silence).[24]

One of the primary outcomes was survival. There was dissonance between the quantitative and qualitative data. The qualitative data showed that participants believed that the decision represented 'do or die', but this was not substantiated by the quantitative data as the quality of the evidence was such that we could not demonstrate a survival advantage with either parenteral nutrition or gastrostomy to allow clinicians to present prolonged survival with any certainty. This dissonance is likely due to patients perceptions, patients viewed that clinicians made the decision for them, often out of clinical necessity.[72] This decision-making process has been echoed by numerous studies[75 76] were patients feel there is no decision to be made if there was only one treatment option. In this case patients make the choice to live and then by necessity accept whatever they perceive will facilitate this, in this case VPG or PN. A further potential for this dissonance could be patients' misconceptions about the benefits of noncurative cancer treatment, highlighted by numerous studies,[77–79] these misconceptions can be influenced by coping mechanisms such as hope and emotional factors that drive decision making.[77 80 81]

Both sources of data were concordant regarding net improvement in QoL despite significant burdens for those with a gastrostomy. No participant regretted insertion and would recommend gastrostomy to others. The QoL parenteral nutrition quantitative data are less clear; for some participants there was obvious improvement, but not for all. However, this was concordant with the qualitative data with a gain for some while others reported significant burdens. However, it appears that participants were willing to live with the burdens because they believed this would bring survival benefit.

For parenteral nutrition, there was silence in both data sources for symptoms, if it is captured at all it is seen as part of QoL data, such as physical function and fatigue. With gastrostomy data findings were concordant: high symptom relief reported quantitatively and echoed in the qualitative data.

With parenteral nutrition there are few data regarding nutritional or performance status. The data available point to a maintenance of performance status for most, with an improvement in some. Nutritional status seems to be improved with parenteral nutrition. In the qualitative data there is some mention of improvements in energy levels or self-reported weight gain. For gastrostomy there is silence on both accounts.

For both health service utilisation and place of death there is silence for both interventions in the qualitative data. This is due to the focus of the research questions which did not explore the impact on place of care and provides questions for future research.

DISCUSSION

We provide the first mixed-methods systematic review and synthesis of PN and PVG in MBO, investigating a range of patient-relevant outcomes. Forty-seven papers, representing 3538 participants, were included.

Both interventions improved QoL, especially with PVG, and on balance for PN, where the benefits outweighed the burdens of the intervention in the context of a perceived threat of death as an alternative. No patients regretted the decision to have a PVG.

We could not determine whether PN prolonged survival, this systematic review found no level 1a (evidence from RCTs) with regard to survival or level 2a evidence (well-designed observational studies which address key confounders), this review echoes that of the Cochrane review.[14] The lack of RCT evidence is discussed below. However, it is notable that for a significant proportion of patients receiving PN, there appears to be a survival advantage of months. This suggests a PN-related survival advantage for particular subgroups such as those with earlier-stage disease unable to tolerate oral and enteral nutrition when compared with starvation.

Two studies compared survival with PN to no PN, but the observational study designs were unable to account for significant confounding baseline variables, such as stage of disease or performance status. The only RCT for PN is one phase-2 trial, comparing IV hydration to PN, with poor recruitment resulting in

insufficient power,[70] the median survival of the PN group was 13 days, highlighting these patients were dying from advanced stage of the tumour not from starvation. It is argued that only if the patients are expected to die from starvation before they die from advanced cancer, there is a rationale for a trial of PN. The need for more definitive data regarding survival is clear, as our qualitative data shows that a belief in increased survival is the primary motivator for patients consenting to treatment.

A key clinical challenge is identifying patients who are likely to survive for long enough to benefit from PN. Existing guidelines[82–84] suggest those with an expected prognosis of 2–3 months or greater, and those with a higher performance status may benefit most from PN with regard to survival. However, our review shows that we do not know whether apparent improvements in survival are merely a feature of baseline performance status (those with better performance status are also those most likely to get PN).

Our median survival ranges are consistent with other work.[15 16] However, included studies used seven different definitions for measuring survival, which, alongside the skewed survival data and various methods for reporting averages, made it inappropriate to combine the study results. Cochrane authors haven taken the same view, finding the same problem.[11 13]

We have no level 1a evidence, or robust evidence from large observational studies which account for confounding variables (especially stage and amount of disease) and documented harms from PN, although again with lack of clarity how these affect any net benefit. Therefore there is ethical equipoise[85] with regards to an RCT—at least in those who do not have stage 1 disease, or a single site of obstruction from localised disease. With unproven effectiveness and documented harms from PN, this should be of concern to clinicians and patients.

However, given the strong belief (clinicians and patients) that death would be due to due to starvation in most, if not all, cases, we recognise that an RCT would be very difficult to carry out due to reluctance of both clinicians and patients regarding randomisation. The unsuccessful phase 2 RCT we include[70] illustrates this challenge, but the authors do not describe their process of consent, or how they may or may not have addressed the issue of equipoise during recruitment and consent. A successful RCT would need careful inclusion criteria (the population where there is most doubt) and extensive education to both clinical site staff and potential participants with regard to ethical equipoise. A well-designed feasibility RCT across several large oncology and intestinal failure centres which included appropriate and well delivered education during recruitment would be needed to assess whether or not a RCT would indeed not be possible.

Survival and PVG use data were largely confounded as many of those who received a PVG also received PN. Unlike PN there is a less strong plausible physiological rationale for a survival benefit, other than the potential of reduced mortality and morbidity through reducing the risk of aspiration. Nonetheless, as with the PN data, patients perceived PVG to provide a survival benefit and again this was a key determinant for agreeing to PVG placement.

Symptoms were improved by PVG but not measured or discussed for PN. Burdens (to patients and carers) were an issue for both interventions, with the reality often at odds with the expected experience, with some not being prepared for the impact of both the process of having the intervention, and of living with it.

Performance and nutritional status appear to be maintained, or improved, by PN. Our review demonstrates a potential relationship between performance status and anticancer treatments which may increase survival in this situation. Nonetheless, for most outcomes data were sparse and drawn from low quality evidence. A potential area of further investigation is whether PN improves performance status enough to allow further anticancer treatment in those previously deemed unsuitable.

For both interventions, health service utilisation and place of death data were variable, and the impact on these outcomes is unclear. Health service utilisation data were descriptive, highlighting that around 80% of patients die at home or in hospice care. Readmissions overall are low, but for a subgroup are many, likely reflective on the varying disease stages and performance statuses. Both interventions appear to allow patients to spend time out of hospital and valuable time at home. One of the largest studies to investigate health service utilisation within MBO[7] concluded that PVG is associated with fewer readmissions and lower intensity healthcare utilisation at the end of life, compared with medical management or surgery.

A place of death outside of hospital could be a motivating factor for choosing these interventions. This was demonstrated in the PN qualitative literature, which highlighted that a key benefit of the intervention was allowing time at home with loved ones. Previous research has also emphasised for those with advanced cancer home care is the most common preferred place of death, with inpatient hospice care as second preference[86]

Of note, no studies compared PN or PVG with medical or surgical management alone. Two RCTs were included in this review, one of which compared PVG to nasogastric tube,[69] showing greater symptom management and QoL for the PVG. This suggests that PVG placement needs to be considered earlier in the decision-making process to avoid repeated nasogastric tube insertions. The second[70] comparing intravenous fluids to PN was only able to recruit 31 of a proposed 116 patients; many patients and families were 'repulsed' by the idea of the study due to their distresses regarding a patient starving to death if allocated to the control arm. The ethical considerations in this area are numerous, and centre on the randomisation of nutrition to patients who are unable to eat, particularly if studies aim to include a 'no treatment arm'. This is an ongoing dilemma and barrier to MBO research[87] and

highlights the importance of accurate understanding and appropriate communication by professionals about the known benefits of interventions. This is evidenced by a paucity of well-designed prospective clinical trials.

Implications for clinical practice and research

It appears PN plays a key role in the management of MBO in allowing patients valuable time at home. However, healthcare professionals need to be aware of the emotional and physical costs that patients and their carers will face. They must present an accurate picture when deciding on treatments. Further data on QoL and survival are necessary before more informed decisions regarding the usefulness of PN in palliative MBO can be made. Due to the feasibility challenges of undertaking RCTs with this intervention, the feasibility of randomisation should be identified before conducting a phase-3 RCT. If proven to be unfeasible, an alternative study design could be a quasi-RCT where patients with IMBO who would qualify for PN but choose not to be treated with PN act as the control group, but again this would be challenging to recruit to given the health beliefs regarding the benefits of PN. Further research in relation to the decision-making processes for PN is also required, and as patients view these decisions as clinician led, a greater understanding of clinicians' decision making process is needed.

It appears that PVG is an effective intervention providing symptoms relief for patients with MBO, allows patients to spend time out of hospital and appears to improve QoL for most. Gastrostomies appear to be an underutilised intervention in clinical practice, and uptake of their use could be improved, though not without realistic information being provided to help patients make more informed decisions on their use. A direction for further research is regarding gastrostomies and patient QoL. As PVG appears to be underutilised, as with PN, a greater understanding of clinicians' decision-making processes is required.

Strengths and limitations

The use of a mixed-methods design is the main strength of this review, with both qualitative and quantitative studies being included in the analysis. This allows the triangulation of results and enables a richer insight into patients' experiences of PN and PVG.

There are several limitations. First, due to varying definitions for outcomes, and study quality, a meta-analysis of extracted data was not possible. Second, the studies or components of studies were judged to be of variable quality and subject to varying risk of bias. Overall, the certainty of evidence was very low, derived mainly from observational studies without a comparator, and without robust adjustment for major confounders. Finally, with the qualitative data few papers were found, illustrating that this is currently under-researched, with PN data drawn from one cohort of women with ovarian cancer, and PVG data drawn from 11 patients, only 1 of which was male.

CONCLUSION

PN and PVG may support patients' valuable time at home.

PVG also provides symptom relief and better QoL, and participants would recommend the intervention to others. We found no high quality evidence to show either intervention prolonged survival, but this was a firm belief by patients and clinicians, providing the context for their decision making. Given the burdens associated with both, and that reality was different to expectations, healthcare professionals must present and honest and realistic account of the benefits and challenges of the treatment options. Well-designed studies should be done to address the knowledge gap regarding survival for both interventions and symptom benefits for PN. We need to identify patients most likely to benefit from PN or PVG.

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Contributors MP and MJJ designed the project. MP, SG and MJJ designed the protocol. MP and SG conducted the literature search. MP, YM, AB and JC performed the screening and quality assessment. MP, YM and AB performed the data extraction. MP and AB performed the analysis. MP drafted the initial manuscript. MP and MJJ have overall responsibility for the final content. MP is guarantor.

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OVID FOR MEDLINE SEARCH STRATEGY

Parenteral nutrition

1 intestinal obstruction/ or duodenal obstruction/ or intestine obstruction/

2 ((bowel* or intestin* or gastrointestin* or gastro intestin* or colon* or colorect* or retrosigmoid*) adj3 (obstruct* or occlu* or block*)).ti,ab,kw.

3 1 or 2

4 exp Genital Neoplasm, Female/ or exp Ovarian Neoplasm/

5 ((ovar* or uterine or vaginal or vulva* or cervi* or gynae* or gyne*) adj3 (neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*)).ti,ab,kw.

6 exp Intestinal Neoplasm/ or digestive system neoplasm/ or gastrointestinal neoplasm/ or peritoneal neoplasm/

7 ((neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*) adj3 (rectal* or colorectal* or anal* or colo* or intestin* or abdominal or digest*)).ti,ab,kw.

8 4 or 5 or 6 or 7

9 Neoplasm/co or *Neoplasm/th

10 ((end stage* or incurable* or advanced*) adj3 cancer*).ti,ab,kw. or palliative care/ or terminal care/ or hospice care/

11 3 and 8 [obstruction and specific cancers]

12 malignan*.ti,ab,kw.

13 3 and 12 [obstruction and maligan*]

14 9 and 10 [cancer complications or focused cancer therapy]

15 11 or 13 or 14

16 exp Parenteral Nutrition/

17 Parenteral Nutrition, Home/

18 (total parenteral nutrition* or TPN* or parenteral nutrition* or PN*).mp.

19 ((parenteral* or artificial* or tub* or catheter* or intraven* or IV* or subcutan* or bypas*) adj3 (nutri* or hydration* or feed* or fed* or treatment* or manag* or method* or car* or support* or diet*)).mp.

20 parenteral nutrition.mp. or parenteral nutrition/ or nutrition supplement/

21 16 or 17 or 18 or 19 or 20 [parenteral nutrition]

22 15 and 21

Gastrostomy

1 intestinal obstruction/ or duodenal obstruction/ or intestine obstruction/

2 ((bowel* or intestin* or gastrointestin* or gastro intestin* or colon* or colorect* or retrosigmoid*) adj3 (obstruct* or occlu* or block*)).ti,ab,kw.

3 1 or 2

4 exp Genital Neoplasm, Female/ or exp Ovarian Neoplasm/

5 ((ovar* or uterine or vaginal or vulva* or cervi* or gynae* or gyne*) adj3 (neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*)).ti,ab,kw.

6 exp Intestinal Neoplasm/ or digestive system neoplasm/ or gastrointestinal neoplasm/ or peritoneal neoplasm/

7 ((neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*) adj3 (rectal* or colorectal* or anal* or colo* or intestin* or abdominal or digest*)).ti,ab,kw.

8 4 or 5 or 6 or 7

9 Neoplasm/co or *Neoplasm/th

10 ((end stage* or incurable* or advanced*) adj3 cancer*).ti,ab,kw. or palliative care/ or terminal care/ or hospice care/

11 3 and 8 [obstruction and specific cancers]

12 malignan*.ti,ab,kw.

13 3 and 12 [obstruction and maligan*]

14 9 and 10 [cancer complications or focused cancer therapy]

15 11 or 13 or 14

16 Gastrostomy/ or Gastroscopy/ or Jejunostomy/ or Gastrostomy*.mp. or Gastroscopy*.mp. or Jejunostomy*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

17 Decompression, Surgical/

18 Intubation, Gastrointestinal.mp. or Intubation, Gastrointestinal/

19 Intubation, Gastrointestinal/

20 gastrointestinal intubation tube/ or duodenum intubation/ or digestive tract intubation/ or stomach intubation/

21 ((gastrosom* or gastroscop* or jejunos* or percutan* or peg* or jej* or decomp* or intub*) adj3 (obstruct* or occlu* or block* or decomp* or intub*)).ti,ab,kw.

22 gastrostomy catheter/ or gastrostomy/ or percutaneous endoscopic gastrostomy tube/ or gastrostomy.mp. or percutaneous endoscopic gastrostomy/ or gastrostomy device/

23 Gastrostom$.mp.

24 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23

25 15 and 24

OVID EMBASE SEARCH STRATEGY

Parenteral nutrition

1. intestinal obstruction/ or duodenal obstruction/ or intestine obstruction

2. ((bowel* or intestin* or gastrointestin* or gastro intestin* or colon* or colorect* or retrosigmoid*) adj3 (obstruct* or occlu* or block*)).ti,ab,kw.

3. 1 or 2

4. exp Genital Neoplasm, Female/ or exp Ovarian Neoplasm/

5. ((ovar* or uterine or vaginal or vulva* or cervi* or gynae* or gyne*) adj3 (neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*)).ti,ab,kw.

6. exp Intestinal Neoplasm/ or digestive system neoplasm/ or gastrointestinal neoplasm/ or peritoneal neoplasm/

7. ((neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*) adj3 (rectal* or colorectal* or anal* or colo* or intestin* or abdominal or digest*)).ti,ab,kw.

8. 4 or 5 or 6 or 7

9. Neoplasm/co or *Neoplasm/th

10. ((end stage* or incurable* or advanced*) adj3 cancer*).ti,ab,kw. or palliative care/ or terminal care/ or hospice care/

11. 3 and 8 [obstruction and specific cancers]

12. malignan*.ti,ab,kw.

13. 3 and 12 [obstruction and maligan*]

14. 9 and 10 [cancer complications or focused cancer therapy]

15. 11 or 13 or 14

16. exp Parenteral Nutrition/

17. Parenteral Nutrition, Home/

18. (total parenteral nutrition* or TPN* or parenteral nutrition* or PN*).mp.

19. ((parenteral* or artificial* or tub* or catheter* or intraven* or IV* or subcutan* or bypas*) adj3 (nutri* or hydration* or feed* or fed* or treatment* or manag* or method* or car* or support* or diet*)).mp.

20. 16 or 17 or 18 or 19 [parenteral nutrition]

21. 15 and 20

Gastrostomy

1 intestinal obstruction/ or duodenal obstruction/ or intestine obstruction/

2 ((bowel* or intestin* or gastrointestin* or gastro intestin* or colon* or colorect* or retrosigmoid*) adj3 (obstruct* or occlu* or block*)).ti,ab,kw.

3 1 or 2

4 exp Genital Neoplasm, Female/ or exp Ovarian Neoplasm/

5 ((ovar* or uterine or vaginal or vulva* or cervi* or gynae* or gyne*) adj3 (neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*)).ti,ab,kw.

6 exp Intestinal Neoplasm/ or digestive system neoplasm/ or gastrointestinal neoplasm/ or peritoneal neoplasm/

7 ((neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*) adj3 (rectal* or colorectal* or anal* or colo* or intestin* or abdominal or digest*)).ti,ab,kw.

8 4 or 5 or 6 or 7

9 Neoplasm/co or *Neoplasm/th

10 ((end stage* or incurable* or advanced*) adj3 cancer*).ti,ab,kw. or palliative care/ or terminal care/ or hospice care/

11 3 and 8 [obstruction and specific cancers]

12 malignan*.ti,ab,kw.

13 3 and 12 [obstruction and maligan*]

14 9 and 10 [cancer complications or focused cancer therapy]

15 11 or 13 or 14

16 Gastrostomy/ or Gastroscopy/ or Jejunostomy/ or Gastrostomy*.mp. or Gastroscopy*.mp. or Jejunostomy*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

17 Decompression, Surgical/

18 Intubation, Gastrointestinal.mp. or Intubation, Gastrointestinal/

19 Intubation, Gastrointestinal/

20 gastrointestinal intubation tube/ or duodenum intubation/ or digestive tract intubation/ or stomach intubation/0

21 ((gastrosom* or gastroscop* or jejunos* or percutan* or peg* or jej* or decomp* or intub*) adj3 (obstruct* or occlu* or block* or decomp* or intub*)).ti,ab,kw.

22 gastrostomy catheter/ or gastrostomy/ or percutaneous endoscopic gastrostomy tube/ or gastrostomy.mp. or percutaneous endoscopic gastrostomy/ or gastrostomy device/

23 Gastrostom$.mp.

24 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23

25 15 and 24

CENTRAL SEARCH STRATEGY

Parenteral nutrition

#1 MeSH descriptor: [Intestinal Obstruction] explode all trees

#2 MeSH descriptor: [Duodenal Obstruction] explode all trees

#3 ((bowel* or intestin* or gastrointestin* or gastro intestin* or colon* or colorect* or retrosigmoid*) near/3 (obstruct* or occlu* or block*))

#4 #1 or #2 or #3

#5 MeSH descriptor: [Intestinal Neoplasms] explode all trees

#6 MeSH descriptor: [Gastrointestinal Neoplasms] explode all trees

#7 MeSH descriptor: [Peritoneal Neoplasms] explode all trees

#8 MeSH descriptor: [Digestive System Neoplasms] explode all trees

#9 MeSH descriptor: [Ovarian Neoplasms] explode all trees

#10 #5 or #6 or #7 or #8 or #9

#11 ((end stage* or incurable* or advanced*) near/3 (cancer or palliative care or terminal care or hospice care))

#12 ((neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*) next/3 (rectal* or colorectal* or anal* or colo* or intestin* or abdominal or digest*))

#13 ((ovar* or uterine or vaginal or vulva* or cervi* or gynae* or gyne*) next/3 (neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*))

#14 #11 or #12 or #13

#15 #10 or #14

#16 #4 and #15

#17 MeSH descriptor: [Parenteral Nutrition] explode all trees

#18 (total parenteral nutrition* or TPN* or parenteral nutrition* or PN*)

#19 ((parenteral* or artificial* or tub* or catheter* or intraven* or IV* or subcutan* or bypas*) near/3 (nutri* or hydration* or feed* or fed* or treatment* or manag* or method* or car* or support* or diet*))

#20 #17 or #18 or #19

#21 #16 and #20

Gastrostomy

#1 MeSH descriptor: [Intestinal Obstruction] explode all trees

#2 MeSH descriptor: [Duodenal Obstruction] explode all trees

#3 ((bowel* or intestin* or gastrointestin* or gastro intestin* or colon* or colorect* or retrosigmoid*) near/3 (obstruct* or occlu* or block*))

#4 #1 or #2 or #3

#5 MeSH descriptor: [Intestinal Neoplasms] explode all trees

#6 MeSH descriptor: [Gastrointestinal Neoplasms] explode all trees

#7 MeSH descriptor: [Peritoneal Neoplasms] explode all trees

#8 MeSH descriptor: [Digestive System Neoplasms] explode all trees

#9 MeSH descriptor: [Ovarian Neoplasms] explode all trees

#10 #5 or #6 or #7 or #8 or #9

#11 ((end stage* or incurable* or advanced*) near/3 (cancer or palliative care or terminal care or hospice care))

#12 ((neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*) near/3 (rectal* or colorectal* or anal* or colo* or intestin* or abdominal or digest*))

#13 ((ovar* or uterine or vaginal or vulva* or cervi* or gynae* or gyne*) near/3 (neoplasm* or tumor* or tumour* or cancer* or malignan* or carcinoma* or adenocarcinoma* or carcinosarcoma* or sarcoma*))

#14 #11 or #12 or #13

#15 #10 or #14

#16 #4 and #15

#17 MeSH descriptor: [Gastrostomy] explode all trees

#18 MeSH descriptor: [Gastroscopy] explode all trees

#19 MeSH descriptor: [Intubation] explode all trees

#20 MeSH descriptor: [Intubation, Gastrointestinal] explode all trees

#21 MeSH descriptor: [Decompression, Surgical] explode all trees

#22 MeSH descriptor: [Enteral Nutrition] explode all trees

#23 Gastros*

#24 #17 or #18 or #19 or #20 or #21 #22 or #23

#25 #16 and #24

EBSCO FOR CINAHL COMPLETE

Parenteral nutrition

malignant bowel obstruction OR (advanced cancer or metastatic cancer or terminal cancer or palliative cancer or cancer) AND (parenteral nutrition or total parenteral nutrition or tpn)

Gastrostomy

malignant bowel obstruction OR (advanced cancer or metastatic cancer or terminal cancer or palliative cancer or cancer) AND gastrostomy

WEB OF SCIENCE

Parenteral nutrition

1 TOPIC: (Intestinal Obstruction* OR malignant bowel obstruction*)

2 TOPIC: (Parenteral nutrition)

3 #2 AND #1

Gastrostomy

1 TOPIC: (Intestinal Obstruction* OR malignant bowel obstruction*)

2 TOPIC: (Gastrostomy)

3 #2 AND #1

For BASE (Bielefeld Academic Search Engine), Caresearch (grey literature), ClinicalTrials.gov, EU Clinical Trials Register and the World Health Organization (WHO) International Clinical Trials Registry Platform (ICTRP) we combined terms for malignant bowel obstruction AND parenteral nutrition or gastrostomy.

Searches prior to deduplication.

Database	Parenteral nutrition (2020)	Gastrostomy (2020)	Parenteral nutrition (2021)	Gastrostomy (2021)
Medline	730	808	56	54
Embase	1394	1243	51	76
Central	148	32	5	1
CINHAL	1212	111	64	49
Web of science	458	181	28	11
Caresearch	269	15	0	0
BASE	515	69	38	0
Clinicaltrials.gov	224	10	0	0
EU Clinical Trials Register	21	16	0	0
WHO ICTRP	9	13	0	0
Citation Searches of Selected key studies of particular importance= 136				

CASP COHORT STUDY CHECKLIST

STUDY	1	2	3	4	5a	5b	6a	6b	7	8	9	10	Comments
Abu-Rustum 1997	?	•	•	•	×	×	•	•	?	×	•	×	unclear aim, risk of biases, risk of confounding, data presentation
Aria Guerra 2015	•	•	•	•	×	•	•	•	•	•	•	•	risk of biases, risk of confounding,
August 1991	•	?	×	×	×	×	•	•	?	?	?	?	risk of biases, risk of confounding, data presentation
Bond 2019	?	•	•	•	×	×	•	•	•	•	•	?	risk of biases, risk of confounding
Bozzetti 2002	•	×	•	•	×	•	•	•	•	•	•	•	risk of biases, risk of confounding,
Brard 2006	•	×	•	•	×	×	•	•	•	•	?	×	risk of confounding, risk of selection bias,
Chermesh 2011	?	•	?	?	×	×	•	•	•	×	•	•	unclear aim, risk of confounding, data presentation
Chouhan 2016	•	•	•	•	•	×	•	•	•	•	•	•	risk of confounding,
Cotogni 2017	•	•	•	•	•	•	•	•	•	•	•	?	
Duerksen 2004	•	•	×	•	×	×	•	•	•	×	•	?	risk of selection bias, risk of confounding, data presentation
Dzierianowski 2021	•	•	×	•	•	•	•	•	•	•	•	•	risk of selection bias,
Fan 2007	?	•	×	•	×	×	•	•	•	×	•	•	risk of selection bias, risk of confounding, data presentation
Keane 2018	•	•	?	•	•	•	•	•	•	•	•	•	risk of selection bias
King 1993	•	•	•	×	×	×	•	•	•	•	•	•	risk of reporting bias, risk of confounding,
Mercadante 1995	?	?	•	•	×	×	•	•	×	×	•	•	unclear aim, risk of biases, risk of confounding, data presentation
Patel 2021	•	•	?	?	•	•	•	•	•	•	•	•	risk of bias, risk of confounding,
Ruggeri 2020	•	•	•	•	×	×	•	•	•	•	•	•	risk of bias, risk of confounding,
Santarpia 2006	?	•	•	•	•	•	×	×	•	•	•	•	unclear aim, risk of bias
Soo 2018	•	•	•	•	×	×	•	?	•	×	•	•	
Adelson 1993	?	?	?	×	×	×	•	•	?	×	•	×	unclear aim, risk of biases, risk of confounding, data presentation
Arvieux 2005	•	•	?	?	×	×	•	•	?	?	?	×	risk of biases, risk of confounding, unclear data presentation
Brooksbank 2002	?	•	•	×	×	×	•	•	?	×	•	•	unclear aim, risk of biases, risk of confounding,
Cannizzaro 1995	•	•	•	•	×	×	?	?	•	?	•	•	risk of biases, risk of confounding,
Champagnutta 1998	•	•	?	•	×	×	?	?	•	•	•	•	risk of biases, risk of confounding,
Cunningham 1995	?	•	•	×	×	×	?	•	?	?	•	•	unclear aim, risk of biases, risk of confounding, unclear data presentation
Diver 2013	?	•	•	•	×	×	•	•	•	•	•	•	risk of biases, risk of confounding,

Dittrich 2017	•	×	•	?	•	•	•	•	•	•	•	•	risk of biases,
Gauvin 2021	•	?	•	•	×	×	•	•	•	•	•	•	risk of confounding,
Goldberg 2021	•	•	•	?	×	×	•	•	•	•	•	•	risk of measurement bias, risk of confounding,
Herman 1992	?	•	×	×	×	×	•	•	?	?	•	•	risk of biases, risk of confounding, data presentation
Issaka 2014	•	?	•	×	×	×	•	•	•	•	•	•	risk of confounding,
Jolicoeur 2003	•	?	•	•	×	×	•	•	?	?	•	•	risk of biases, risk of confounding, unclear data presentation
Kawata 2014	•	?	•	×	×	×	?	•	•	•	•	•	risk of reporting biases, risk of confounding,
Lilley 2018	•	?	•	•	•	•	•	•	•	•	•	?	risk of selection bias
Merchant 2020	•	•	•	•	×	•	•	•	•	•	•	•	risk of confounding,
Pothuri 2005	•	•	•	•	×	×	•	•	•	•	•	•	risk of biases, risk of confounding
Rath 2013	•	•	•	•	×	×	•	•	•	•	•	•	risk of biases, risk of confounding
Scheidbach 1999	?	•	•	×	×	×	•	•	•	•	•	•	risk of biases, risk of confounding,
Teriaky 2012	•	•	•	•	×	×	?	×	?	•	×	•	risk of biases, risk of confounding, unclear data presentation
Vashi 2012	?	•	•	×	×	×	?	?	•	?	•	•	unclear aim, risk of biases, risk of confounding, unclear data presentation
Zucchi 2016	•	•	•	•	×	×	•	•	•	•	•	•	risk of confounding,

CASP QUALITATIVE STUDIES CHECKLIST

STUDY	1	2	3	4	5	6	7	8	9	10	Comments
Sowerbutts 2019	•	•	•	•	•	?	•	•	•	•	unclear reflexivity in research design,
Sowerbutts 2020a	•	•	×	•	•	×	•	•	•	•	unclear reflexivity in research design, unclear research design justification
Sowerbutts 2020b	•	•	•	•	•	?	•	•	•	•	unclear reflexivity in research design,
Singh curry 2019	•	•	•	•	•	×	•	•	•	•	unclear reflexivity in research design,

ROB 2: A REVISED COCHRANE RISK-OF-BIAS TOOL FOR RANDOMIZED TRIALS

Oh 2014		
Bias	**Authors' judgement**	**Support of judgement**
Random sequence generation (selection bias)	Low risk	Permuted-block randomization
Allocation concealment (selection bias)	Low risk	Allocated group was announced to investigators at the time of assignment of each patient by telephone call
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Insufficient information to permit judgement
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Insufficient information to permit judgement
Incomplete outcome data (attrition bias) All outcomes	High risk	The study was closed early because of poor patient accrual, and it was expected that the target population could not be achieved within the study time frame.
Selective reporting (reporting bias)	Low risk	No evidence of selective reporting.
Other bias	Unclear risk	Possible inclusion bias

Aramaki 2019		
Bias	**Authors' judgement**	**Support of judgement**
Random sequence generation (selection bias)	Unclear risk	Insufficient information to permit judgement
Allocation concealment (selection bias)	Unclear risk	Insufficient information to permit judgement
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Open -but assessor(s) are blinded
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Insufficient information to permit judgement
Incomplete outcome data (attrition bias) All outcomes	Low risk	No missing outcome data
Selective reporting (reporting bias)	Unclear risk	Insufficient information to permit judgement
Other bias	Low risk	The study appears to be free of other sources of bias

Characteristics of Included Studies

Author, Year, Study Design and Location	Study Aim	Sample Size, Age, Sex and % with MBO	Cancer Diagnosis and Treatment	Definition of survival	Survival	HRQoL
Parenteral Nutrition						
Abu-Rustum 1997 Retrospective cohort study USA	To determine the efficacy of intravenous chemotherapy alone or with PN in restoring bowel function	21 Mean 54.5 years (range 32 to 75) *F* n= 21 100%	*Diagnosis* Advanced ovarian cancer *Treatment* Chemotherapy with a median of three regimens prior to developing intestinal obstruction (range two to six regimens).	From venting gastrostomy insertion	Median for those who received salvage chemotherapy was 89 days, longer than for patients who received salvage chemotherapy alone (71 days) (P =0.031).	NR
AriaGuerra 2015 Prospective cohort study Spain	Aimed to analyse the effects of parenteral nutrition in oncologic patients with intestinal occlusion and peritoneal carcinomatosis regarding prognosis	55 60±13 years Sex- NR 100%	*Diagnosis* • Gastrointestinal tumours n= 38 • Gynaecological tumours n= 10 • Other n= 7 *Treatment*- NR	From starting PN to death	Median 40 days (range 2-702)	NR
August 1991 Retrospective cohort study USA	To review the Yale-New Haven Hospital experience with HPN in MBO	18 median 58 years (range 33 to 79) *F* n= 13	*Diagnosis* • Ovarian n=9 • Colon n=4 • Endometrium n= 1	From discharge to death	Median 53 days (range 5-208 days)	For 11 patients all agreed the HPN was beneficial or highly beneficial. In three patients

	patients to determine the efficacy, safety, and indications for HPN in this patient population.	*M* n= 4 100%	• Appendix n= 2 • Stomach n= 1 *Treatment*- NR			the therapy was not beneficial.
Bond 2019 Retrospective cohort study UK	To assess the impact of a novel remote discharge pathway for palliative HPN patients	82 Mean 57 (range 24–80) *F* n= 66 *M* n= 16 100%	*Diagnosis* • Ovarian n= 41 • Peritoneal n= 7 • Colorectal n= 7 • Gastric n= 5 • Lymphoma n= 2 • Neuroendocrine tumour n= 4 • Pseudomyxoma n= 4 • Breast n= 3 • Endometrial n= 3 • Bladder n= 3 • Unknown n= 2 • Sarcoma n= 1 *Treatments-NR*	From discharge to death	Mean 134.8 days(1–1715 days)	NR
Bozzetti 2002 Prospective cohort study Italy	To investigate changes in the quality of life in cancer patients during HPN and to determine whether it is possible to predict length of survival before administering HPN	69 Mean 54 years (range 29–82) *F* n= 28 *M* n= 41 84%	*Diagnosis* • Colorectal n= 21 • Stomach n= 16 • Uterus/ovary n= 13 • Breast n= 2 • Other n= 17 *Treatment*- NR	From starting PN to death	Median 4 months (range 1–14)	Rotterdam symptom checklist (RSCL)-regards to physical, psychological and activity assessment, roughly half patients deteriorated and 40% improved

						with a small percentage of patients who showed no change. In contrast, only one-fourth of patients showed a worsening of the well-being assessment. The median changes were not significantly different from 0 for all the assessments.
Brard 2006 Retrospective cohort study USA	The goal of this retrospective cohort study was to investigate the role of TPN in terminally ill epithelial ovarian cancer patients with terminal intestinal obstruction (TIO) and its effects on survival after TIO diagnosis and any potential complications of this therapy	55 Mean 56.4 years (SD 11.7) *F* n= 55 100%	*Diagnosis* Patients with stage IIIC/IV epithelial ovarian cancer *Treatment* All patients were previously treated with paclitaxel/platinum following cytoreductive surgery.	From time of MBO diagnosis	Patients survived a median of 72 days (range 16–485) if they received TPN compared to 41 days (range 4–133) if no TPN was administered. The mortality rate ratio for TPN users compared to non-users was 0.59 (95% CI: 0.35–1.00).	NR

Chermesh 2011 Prospective cohort study Isreal	To define the role of PN in patients with MBO	28 Mean 59.9 ± 12.7 years F n= 13 M n=15 82%	Diagnosis • Ovary n= 9 • Stomach n= 8 • Colon n= 4 • Pancreas n= 3 • Breast n= 2 • Squamous cell carcinoma of the larynx presumed n= 1 • Carcinoid presumed n = 1	Not defined	Median 140 days (range 20–783) with no difference with regard to age, gender, primary diagnosis, BMI, percentage of weight loss, albumin level and occurrence of TPN-related complications. Patients with KPS > 50 had significantly longer survival than patients with KPS < 50 62 days (range 20–141) vs 211 days (range 50–783).	NR
Chouhan 2016 Retrospective cohort study USA	To examine a large, single-institution dataset to describe outcomes associated with concurrent TPN and systemic chemotherapy for persistent MSBO after conservative management.	82 Median 55 years (range 17–85) *F* n= 51 *M* n= 31 100%	*Diagnosis* • Gastrointestinal n= 49 • Gynecological n= 18 • Other n= 15 *Treatment* Chemotherapy 1st line 38 (46.3%) 2nd line 15 (18.3%) ≥3rd line 29 (35.3%) New chemotherapy start during TPN- 58 (70.7%)	From the initial date where TPN supplementation and chemotherapeutic intervention coincided	Median survival 3.1 months (range, 0.03–69.4 months), with a 1-year overall rate of 12.2%. The median duration of TPN was 45 days (range, 9–639)	NR
Cotogni 2017	To analyse the quality of life in advanced cancer	111	*Diagnosis* • Stomach n= 38	From discharge	Median 4.7 months, (range 1–42)	Patients with advanced malignancy

Prospective cohort study Italy	patients on HPN, and to investigate whether the combination with oncologic treatments correlates with changes in quality of life.	Median 62 years (range 32 to 79) *F* n= 54 *M* n= 57 90%	• Colon/rectum n= 21 Pancreas/biliary system n= 20 • Oesophagus n= 10 • Lung n= 10 • Ovary n= 2 • Others n= 10 *Treatment* Chemotherapy n= 61 Radiation therapy n= 2 Both treatments n= 9	with HPN to death		requiring a nutritional supplementation through HPN maintained their QoL or even showed an improvement in some scores according to the EORTC QLQ-C30. The items which significantly improved were the domains of global QoL, physical, role, and emotional functioning, as well as appetite loss and fatigue.
Deurksen 2004 Retrospective cohort study Canada	The objective of this study was to determine whether a subgroup of patients with intestinal obstruction would benefit from support with TPN, identify factors that might predict patients who would benefit from home	9 Mean- 45 (range 35 to 57) *F* n= 3 *M* n= 6 100%	*Diagnosis* • Gastric n= 4 • Colon n= 4 • Cholangiocarcinoma n= 1 *Treatment*- NR	From starting PN to death	Median 84 (range 26 to 433 d)	NR

	TPN and identify issues relevant for prospective study.					
Dzierianowski 2021 Retrospective cohort study Poland	To verify the overall survival and impact of the overall performance status, clinical symptoms, and laboratory test results at HPN initiation on patients' survival probability with MBO	114 Mean (95% CI)- 54.7 (52.5–56.9) *F* n= 81 *M* n= 33 100%	*Diagnosis* • Colorectal n= 19 • Stomach n= 40 • Other gastroenterological n= 7 • Gynecological n= 33 • Ovarian n= 25 • Other gynecological n= 8 • Other n= 15 *Treatment*- NR	From starting PN to death	Median (Q25–Q75) 89 (52–186) (range, 16–1393) Survival based on ECOG • 0 Median 680 (range 543–1393) • 1 Median 174 (range 65–748) • 2 Median 61.5 (range 25–399) • 3 Median 26 (range 16–64)	NR
Fan 2007 Retrospective cohort study China	The purpose of the study was to explore life expectancy in the patient with advanced cancer who received PN after cessation of energy intake due to malignant GI tract obstruction.	115 Mean- 51 (range, 31–74) *F* n= 62 *M* n= 53 100%	*Diagnosis* • Gastric carcinoma n= 24 • Colorectal carcinoma n= 23 • Oesophageal carcinoma n= 20 • Jejunal carcinoma n= 14 • Breast carcinoma n= 10 • Sarcoma n= 9 • Cholangiocarcinoma n= 9 • Pancreatic carcinoma n= 3 • Lymphoma n= 3	From the initiation of PN to death	Mean 6.5 months Eleven patients survived ≥1 year and 2 patients have been alive for almost 4 years later after cessation of energy intake.	NR

			Treatment- NR			
Keane 2018 Retrospective cohort study UK	To examine the prognostic significance of performance status, type and site of tumour, previous or concurrent chemo-radiotherapy, anthropometric characteristics, nutritional and inflammatory status, demographic characteristics, serum biochemistry, and prognostic indices based on a large cohort of patients with advanced cancer receiving HPN at University College London Hospitals	107 Mean age 57 ± 12 years *F* n= 68 *M* n= 39 74.3%	*Diagnosis* • Gynaecological n= 37 • Upper Gastrointestinal n= 21 • Lower Gastrointestinal n= 24 • Hepato-pancreatobiliary n= 10 • Haematological n= 5 • Other n= 10 Most patients had metastatic disease (81.3%) *Treatments* Most patients had undergone surgery for their malignancy (79%), or chemotherapy before and/or during PN administration (90.4%). The majority of patients were radiotherapy naive (71.2%).	Measured from discharge until death	Overall mean survival was 30.8 weeks (95% CI 21.4–39.6) and median survival was 14 weeks (IQR 5–34).	NR
King 1993 Retrospective cohort study USA	1) Review our experience of in gynaecological cancer patients who received HPN. 2) determine if	61 Age- mean 55.0 years. *F* n= 61	*Diagnosis* • Ovarian n= 34 • Cervix n= 15 • Corpus n= 9 • Vulva n= 2 • Vagina n =1	Date of initiation of HPN to last follow-up or death	Mean 167.5 days, median 60 days (range 2-780 days)	Prior to HPN starting versus during HPN KPS 48 47

	HPN improved patients nutrition parameters, survival and quality of life	72%	*Treatment* Surgery n= 60 Chemotherapy n= 56 Radiotherapy n= 43 30 patients had been treated with all three modalties, and 27 had been treated with two modalities. *Treatment received during HPN* Surgery n= 14 Chemotherapy n= 31 Radiotherapy n= 7 *Doesn't state surgery for resolution of MBO.			Activity level 3.8 3.5 Pain 2.6 2.3 GI discomfort 2.8 2.4 N & V 3.2 2.7 Fatigue 3.4 3.0 Diarrhoea 2.0 1.8 Morale 2.7 2.5 Social interaction family/friends 2.8 2.5 Note, 1, usual or best; 5, worst or never.
Mercadante 1995 Retrospective cohort study Italy	To describe clinical experience with HPN patients	13 Age- mean 56 years (32 to 71) *F* n= 8 *M* n= 5 100%	*Diagnosis* • Pharynx n= 1 • Colon n= 4 • Stomach n= 1 • Breast n 1 • Ileum n 2 • Ovary n 2 • Oesophagus n= 1 • Pancreas n= 1	From the initiation of PN to death	Mean 30.4 days (range 3-121 days)	NR

			Treatments- NR			
Oh 2014 Randomised control trial South Korea	To investigate the effect of PN on prolonging survival at the end of life in patients with terminal cancer	16 Age (years) 60.4 ± 12.6 *F* n= 6 *M* n= 10 100%	Diagnosis • Hepatobiliary and pancreas n= 2 • Colon n= 4 • Stomach n= 4 • Breast n= 1 • Neuroendocrine n= 2 • Lung n= 1 • Prostate n= 1 • Salivary gland n= 1 *Treatments*- NR	Survival was defined as the time from randomisation to death or to withdrawal from the study.	Median survival of the PN group was 13 days (95% CI, 3.1–22.9 days) median survival of the control group was 8 days (95% CI, 5.7–10.3 days)	NR
Patel 2021 Retrospective cohort study UK	To examine i) what characterizes the MBO population, ii) what medical and nutritional care do patients with MBO who are referred or not referred for nutrition receive and iii) if any of these care pathways affect survival.	72 mean (SD) 63.1 (13.1) years *F* n= 57 *M* n= 15 100%	*Diagnosis* • Gynaecology n = 36 • Lower GI n= 19 • Upper GI n= 3 • HPB n= 3 • Urology n= 2 • Haematology n= 1 • Breast n= 1 • Other n= 6 *Treatment* Prior surgery for cancer n= 32 Prior radiotherapy n= 17 Prior chemotherapy n= 52	From admission with MBO to death or censorship	Median (range) 20 (5.9–65.1) weeks (4.7 (1.4–15.2) months. There was a survival advantage in those in the HPN group vs. those who may have required PN group (323 vs. 91 day, respectively P= 0.0021).	NR
Ruggeri 2020 Retrospective cohort study	To describe the selection criteria used for identifying the eligible patients	629 mean ± SD 64.2 ± 12.6	*Diagnosis* • Gastrointestinal tract n= 319	Date of initiation of HPN to last	Survival (weeks) (n= 564) - Mean (SD) 16.1 (18.0), median (95% C.I.) (9.0-11.3)	NR

Italy	for home artificial nutrition (HAN), and to evaluate the impact of HAN on performance status and survival in cancer patients assisted at home by a palliative care program.	*F* n= 305 *M* n= 324 77.8%	• Head-neck n= 104 • Other organs n= 114 • Lung n= 20 *Treatments*- NR	follow-up or death	KPS at the entry was significantly associated with estimated survival time: a higher KPS at the start of HAN predicted a longer survival [odds ratio 1⁄4 0.9, p < .001,] HPN not separated out from HAN as a whole.	
Santarpia 2006 Retrospective cohort study Italy	To identify predictors of survival in patients with carcinomatosis on home parenteral nutrition	152 Mean 57.8 +/- 13.6 years. Median 59.5 years (Range: 22.0 - 88.0 years) *F* n= 107 *M* n= 45 100%	*Diagnosis* • Stomach n=48 • Ovarian n= 42 • Colorectal n = 30 • Endometrium n = 7 • Breast n = 6 • Iluem n = 5 • Gallbladder n = 4 • Pancreas n = 3 • Kidney n = 2 • Skin n = 1 • Prostate n = 1 • Abdominal sarcoma n = 1 • Unknown n = 2 *Treatments*- "These patients were considered terminal because they were unresponsive to any oncologic treatment"	Date of initiation of HPN to death	Median 45 days (range, 6–1269).	NR
Soo 2018	To describe the patient-related	38	*Diagnosis*	Not specified	Mean survival 5.4 months (range 0.25–33).	NR

Retrospective cohort study Canada	variables in a cohort of advanced cancer patients (ACPs) enrolled in a HPN program	48.76 years (SD 13.8) *F* n= 27 *M* n= 11 84.2%)	• Ovarian n=13 • Colonic n=6 • Gastric n=6 • Peritoneal n=3 • Unknown n=2 • Oesophageal n=2 • Carcinoid n=1 • Cervical n= • Ampullary n=1 • GIST n=1 • Anaplastic large-cell lymphoma n=1 • Rectal n=1 *Treatment* Chemotherapy n=14 Chemotherapy and radiotherapy n=1 None n = 23		Start of HPN KPS > 50 (median 70, IQR 68.75 - 81.86), had a 6-month median duration of life (IQR 2.75 - 9.5). Start of HPN KPS <50 (median 50, IQR 45 - 50), had a median survival of 3 months (IQR 1.75-3.5), p=0.02; two-tailed.	
Sowerbutts 2019 Mixed-methods study UK	To investigate the experience of HPN for women with ovarian cancer and MBO and their family members acting as caregivers, in the context of the nutritional status and survival of a cohort of patients	38 Age, mean ± SD- Interviewed 67 (7.5), not interviewed 64 (10.1) *F* n=38 100%	*Diagnosis* All patients diagnosed with ovarian cancer. *Treatment*- NR	From admission with MBO	Median for all 38 women was 70 days (range 8 to 506). Median for 32 women who received PN was 81 days (range 10 to 506). Median for the 17 patients who had HPN was 156 days (range 46–506). Median for 6 women who did not receive PN was 20 days (range 8 to 109).	Qualitative synthesis.

	with ovarian cancer and MBO.					

Author, Year, Study Design and Location	Study Aim	Sample Size, Age, Sex and % with MBO	Cancer Diagnosis, Treatment	Definition of survival	Survival	Symptoms	HRQoL
Palliative Venting Gastrostomy							
Aramaki 2019 Randomised control trial Japan	To evaluate the superiority of PTEG over NGT as palliative care for bowel obstruction in patients with terminal malignancy from the perspective of patient QOL	40 (21 PEG, 19 NGT) Mean 59.3, Median 32 (Range 34-76) F n= 14 M n= 25 100%	*Diagnosis* 21 PTEG group • Colorectal n= 10 • Stomach n= 6 • Ovarian n= 2 • Bile duct n= 2 • Pancreatic n= 1 19 NGT group • Stomach n =6 • Colorectal n= 3 • Pancreatic n= 3 • Ovarian n= 3 • Peritoneal mesothelioma n= 2 • Oesophageal n= 1 • Bile duct n= 1 • Unknown primary n= 1 *Treatment*- NR	From gastrostomy placement	50 days for the PEG group and 86 days for the NGT group	Included in HRQoL	Mean EQ-5D scores for the PTEG and NGT groups were 7.132 (4.543–9.702) and 3.663 (0.464–6.862), respectively. Mean SF-8 scores were 420.1 (282.6–557.6) and 199.4 (22.2–376.6), respectively.
Adelson 1993	Evaluate the effectiveness of a percutaneous	13	Diagnosis • Ovarian n= 9	Length of tube placement	median 62 days (range 5-246) one	All gastrostomy tubes provided	NR

Retrospective cohort study USA	technique for placement of a drainage gastrostomy.	Median-61 (range 42-78) *F* n= 13 100%	• Cervical n =2 • Papillary peritonela serous tumour n= 1 • Breast n= 1 *Treatment* Prior laparotomies median two (range 1-4)		tube removed electively 131 days after resolution of SBO	GI driainage and relief of n&v and abdo pain due to distention.	
Arvieux 2005 Prospective cohort study France	To draw up a specific medicosurgical protocol for immediate response to the start of bowel obstruction in cancer patients with end-stage peritoneal carcinomatosis who cannot receive curative treatment.	10 Mean 57.9 years (median at 62.5, range 22–84) F n= 8 M n= 2 100%	*Diagnosis* • Ovarian n= 6 • Pancreas n=1 • Stomach n=1 • Bladder n=1 • Melanoma n=1 *all causing carcinamatosis.	From gastrostomy placement	median 13 days (range 6 to 125 days)	100% relief of symptoms	NR
Brooksbank 2002 Retrospective cohort study Australia	An update of our preliminary experience with palliative venting gastrostomy (PVG), which was first reported in 1991	51 61 years (range 25±86 years) *F* n= 32 *M* = n 19	*Diagnosis* • Colon and rectum n= 27 • Ovary n= 16 • Breast n= 2 • Pancreas n= 2 • Other n= 4 *Treatment* All had previous surgery. All patients had been treated with various first-line anti-emetic agents,	From gastrostomy placement	median survival 17 days (range 1±190)	For 47/51 (92%) patients, the symptoms of nausea and vomiting were substantially or completely relieved	Many patients were also able to resume some degree of oral intake of soft food and drink. This was usually seen by both patients and families as a

			mainly metoclopramide, haloperidol and prochloperazine, alone or in combination. Dexamethasone was used in six patients. Octreotide was used in three patients.				positive outcome.
Cannizzaro 1995 Prospective cohort study Italy	To assess their experience in performing endoscopic gastrostomy in patients with obstructing disseminated abdominal cancers, also compared the efficacy of two catheters of different sizes, 15 and 20 Fr respectively, in obtaining symptomatic relief.	22 Mean 53.7 (range 29-73) *F* n= 22 100%	*Diagnosis* • Ovarian n= 14 • Endometrial n =5 • Colon n= 3 *Treatment* Previous abdominal surgery reported for all participants.	From gastrostomy placement	Mean 74 days (Range 13-272)	100% of patient had reduced symptoms. 100% of patients tolerated soft and liquid foods after PEG placement.	NR
Champagnutta 1998 Retrospective cohort study Italy		64 56 (range 20- 76) years *F* n= 56 100%	*Diagnosis* • Colon n= 9 • Stomach n = 2 • Gallbladder n= 2 • Breast n= 1 • Ovarian n =41 • Vagina n= 3 • Endometrium n= 3 • Gynaecological sarcoma n = 3 *Treatment*- NR	From gastrostomy placement	Median 57 dasy (range 4-472)	In 49/64 (76.5%) symptomatic well-being was obtained after a few days of PEG	NR

Cunningham 1995 Retrospective cohort study USA	To evaluate the use of percutaneous decompression gastrostomy in patients with gynaecologic malignancies. Evaluated for successful gastric decompression, acute and long-term complications, and palliation of symptoms.	20 Mean 52 (range 31-73) *F* n= 20 100%	*Diagnosis* • Ovary n= 10 patients • Uterine corpus n= 6 • Cervix n= 3 • Peritoneum n= 1 All patients had recurrent gynaecologic malignancies. *Treatment* • Three patients had undergone previous paracentesis. • Nineteen patients had undergone at least one prior laparotomy (mean 2.2, range 1–6). • Eight patients had received prior radiation therapy including whole abdominal radiation in 2 patients, extended field radiation in 4 patients, and pelvic radiation in 2 patients.	Length of tube placement	Mean 53 days (range 7-184 days) (Seventeen patients continued gastrostomy drainage until the time of death.)*	All patients had significant relief of nausea and emesis except two who had persistent nausea despite adequate gastric decompression	NR
Diver 2013 Retrospective cohort study USA	To review a single institution's experience with gastrostomy tubes (GTs) performed for malignant bowel obstruction from gynecologic cancers.	115 Median-57 (range 26–88) *F* n = 115 100%	*Diagnosis* Ovarian/fallopian tube/PPC n= 96 Cervical n= 6 Uterine (epithelial and stromal) n =13 *Treatment* Chemotherapy (No. of lines of received prior to GT) 1 n= 20 2 n= 22	From gastrostomy placement	Median 5.57 weeks (range 1 day–5.5 years)	NR	NR

			3 or more n= 67 • Unknown- 6				
Dittrich 2017 Retrospective cohort study Germany	Investigate the quantity of symptom relief realized with PEG and the corresponding complications.	76 Median- 66 (range 23-86) F n= 53 M n =22 100%	*Diagnosis* •Ovarian n= 24 •Colorectal n= 13 •Pancreatic n= 12 •Small intestine n= 5 •Gallbladder/biliary tract n= 5 •Gastric n= 4 •Breast n= 3 •CUP n= 3 •Other n= 6 *Treatment*- NR	From gastrostomy placement	Median 28 days (range 2–440).	Without a NG tube or PEG, the mean frequency of vomiting per day was 2.2. The use of a NG tube led to a reduction of daily vomiting to 0.8, and the PEG to a more decreased value of 0.4. PEG reduced the daily frequency of vomiting to 18% of the initial value and the probability to suffer from nausea to 50% (both $p < 0.001$).	NR
Gauvin 2021 Retrospective cohort study USA	To better understand the risks, benefits, and practices associated with the placement and maintenance of palliative G-tubes in	55 Mean ± SD (range), years, 59.5 ±	*Diagnosis* • GI, pancreas, or liver n= 24 • Thoracic/eosphageal n= 3 • Gynaecologic/Genitourinary n= 26 • Other n= 2	from the date of gastrostomy placement to the date of death or last follow-	Survivial % 30 d 54.8 1 y 11.4 3 y 9.5	NR	NR

	patients with cancer at our institution	11.3 (35–88) 100%	*Treatment* Chemotherapy within 3 months of placement n= 16	up visit, with patients alive at last follow-up considered censored			
Goldberg 2021 Retrospective cohort study USA	To describe the clinical outcomes after dPEG in patients with MBO and explore patients'understanding of their illness and expectations forthe future	125 Median 62 years (range, 33-95 years) *F* n= 65 *M* n= 60 100%	*Diagnosis* • Colorectal adenocarcinoma n=41 • Pancreas/ampullary adenocarcinoma n=30 • Gastric/esophageal/GE junction adenocarcinoma n=22 • Appendiceal adenocarcinoma n=15 • Bile duct/gallbladder adenocarcinoma n=8 • Small intestine adenocarcinoma n=4 • Adenocarcinoma of unknown primary n=2 • Colorectal neuroendocrine n=2 • Pancreas/ampullary neuroendocrine n=1 *Treatment*- NR	From gastrostomy placement	Median 37 days (95% CI, 29 to 45 days)	NR	NR
Herman 1992 Retrospective cohort study USA	Report the use of Percutaneous endoscopic gastrostomies for decompression of the	50 Mean- 54 (range 20 to 79)	*Diagnosis* •Ovary- 26 •Colon- 5 •Stomach- 5	Length of tube placement	Mean 66 days (range, 8 to 639 days)	Only three patients (6%) continued to have recurrent nausea post-	NR

	obstructed gastrointestinal tract.	*F* n = 42 *M* n= 11 100%	•Pancreas- 4 •Melanoma- 4 •Endometrial- 4 •Breast- 1 •Renal- 1 *Treatment* Non-surgical candidates and had failed chemotherapy			procedure that was not due to drainage tube impaction and was felt to be a result of central nervous system alteration. Following successful placement, 87% of the patients tolerated a full liquid diet and 56% were also able to ingest soft foods.	
Issaka 2014 Retrospective cohort study USA	To determine the outcomes of VPEG placement in patients with advanced malignancy	96 median 57 (range 21–90) F n= 57 M n= 39 100%	*Diagnosis* •Colorectal n= 26 •Pancreas n= 18 •Gynaecological n= 17 •Gastric n= 6 •Other n= 29 *Treatment*- NR	From gastrostomy placement	mean 135 ± 347.9 days (range 5–2,772 days)	Complete relief of nausea and vomiting was observed in the majority of patients (n = 81, 91.0 %)	NR
Jolicoeur 2003 Retrospective cohort study Canada	To explore whether or not successful symptom control was achieved when using a PEG tube in patients with recurrent ovarian/peritoneal	24 Age- NR F n= 24 100%	*Diagnosis* Ovarian n= 24 *88% (n=21) also presented with a diagnosis of recurrent/progressive ovarian cancer	From gastrostomy placement	median 42 days (range 5 to 1226)	At the time of discharge, 75% of patients were relieved of nausea and 88% no longer	NR

	cancer and bowel obstruction		*Treatment* 19 patients had been surgically debulked and 22 had received chemotherapy			vomited; 17% of patients complained of abdominal cramping and abdominal bloating was experienced by only 17% of patients. By discharge, 92% of patients were able to resume some type of oral intake.	
Kawata 2014 Retrospective cohort study Japan	To evaluate the outcomes and safety of PEG for bowel decompression in a relatively larger number of patients with malignant bowel obstruction	76 Median 62 years (range 21–83) *F* n=- 32 *M* n= 44	*Diagnosis* •Pancreatic cancer n= 27 •Colorectal cancer n= 9 •Gastric cancer n= 8 •Duodenal cancer n= 2 •Other gastrointestinal cancer n= 9 •Gynecological cancer n=7 •Urological cancer n=5 •Other primary malignancy n= 9 Peritoneal carcinomatosis - Absent 20, Present 56. *Treatment* •Chemotherapy n= 46 •Best supportive care n= 30	From gastrostomy placement	median 63 days (range 8–444)	Successful symptom relief was achieved in 53/55 of our patients	NR

Lilley 2018 Retrospective cohort study USA	To compare the following outcomes after treatment for MBO among patients with stage IV ovarian or pancreatic cancer: 1) survival; 2) readmission for MBO; 3) EOL care outcomes, including hospice enrollment, ICU care in the last days of life, and location of death in an acute care hospital.	249 65-74 years n= 119 (47.8%) 75-84 years n= 109 (43.8%) ≥ 85 years n = 21 (8.8%) *F* n= 212 *M* n= 37	*Diagnosis* Ovarian n= 181 Pancreas n= 68 *Treatment*- NR	From admission with MBO	Median 38 (IQ range, 23-69) days.	NR	NR
Merchant 2020 Retrospective cohort study Canada	To (1) examine the incidence of IO, (2) describe current management of IO, and (3) explore the relationship between IO management and patient outcomes in a population-based cohort of patients with colorectal, ovarian, gastric, and pancreatic cancers in Ontario, Canada, in the last year of life.	202 Age- NR Sex- NR 100%		Not defined	Median survival 47 days (IQR: 27-78)	NR	NR
Pothuri 2005 Retrospective cohort study	To analyze the feasibility of using percutaneous endoscopic	94 Age- Mean 56	*Diagnosis* Ovarian n=	From gastrostomy placement	median weeks (95% CI, 6–10)	Symptomatic relief—the absence of nausea or	NR

USA	gastrostomy (PEG) tube placement in ovarian cancer patients with malignant bowel obstruction and to analyze the outcome of these patient	years (range 27-78) F n= 94 100%	The majority of the patients (97%) had stage III or IV disease. *Treatment* 89% had received three or more chemotherapy regimens prior to PEG tube placement. Mean laparotomies prior to PEG tube placement was 1.94 (range, 1–6). Thirty-seven of 94 patients had previous gastrointestinal surgery.			vomiting—was noted in 86 (91%) of 94 patients with successful PEG tube placement, the mean number of days to achieve relief was 1.7 days. Diet tolerated with and without the PEG tube being clamped was as follows: none, 3; sips, 9; liquids, 40; soft/regular, 40; and unknown, 2.	
Rath 2013 Retrospective cohort study USA	To evaluate perioperative and survival outcomes of ovarian cancer patients undergoing percutaneous upper gastrointestinal decompression for malignant bowel obstruction	53 Age-median 60 years (range 38–78 years) F n= 53 100%	*Diagnosis* •Ovarian •Fallopian tube •Primary peritoneal cancer *Numbers not reported *Treatment* Chemotherapy- median of 3 regimens, median time since last cycle of chemotherapy prior to	From gastrostomy placement	median s 46 days (range 2–736 days)	Forty-nine patients (92.5%) experienced control of symptoms (nausea and vomiting), defined as resolution of symptoms prior to	NR

			gastrostomy placement was 1.4 months.			discharge; however, 46 patients required supplemental anti-emetic medication. Forty-eight (91%) patients were able to tolerate some form of oral intake: regular diet (8), soft diet (6) and liquid diet (34). Two patients tolerated tube feeds only and 2 patients were unable to tolerate any form of dietary intake.	
Scheidbach 1999 Retrospective cohort study Germany	In addition to establishing indications and outcome, were to identify specific aspects of tube placement and to determine the incidence of complications.	24 Mean age 64 years (range 37 – 83 years) Sex – NR	NR	From gastrostomy placement	Average survival for the patients discharged home (20/24) was 21 weeks (range, 6–52 weeks)	documented as 24/24 (100%) relief as NGT not needed. Twenty-two patients (92%) were also soon able to take liquids or soft	NR

		100%				foods by mouth.	
Teriaky 2012 Retrospective cohort study Canada	To determine the efficacy of venting PEG tubes in relieving nausea and vomiting	7 Age- mean 62 (range 37-82) F n= 4 M n= 3 100%	*Diagnosis* •Colon n= 3 •Pancreas n = 2 •Other n= 2 *Treatment* •Surgery n= 6 •Adjuvant chemotherapy n= 5 •Radiotherapy n= 2 None of the patients underwent any further surgery, chemotherapy, or radiation therapy after insertion of a venting PEG.	From gastrostomy placement	mean a 119 days (range 6-484 days)	There was relief of nausea and vomiting in 6 (86%) patients on the first day after PEG tube insertion, which persisted throughout hospitalization. Two patients were able to tolerate liquids and 3 patients were able to tolerate food.	NR
Vashi 2012 Retrospective cohort study USA	Not stated	73 Age- Mean 53.3 years (range: 22.3–69 years) F n= 54 M n= 19 100%	*Diagnosis* Majority (n = 27) had cancers of the female genital tract and stage III (n = 22) or IV (n = 27) disease at diagnosis, others not reported. All had advanced abdominal carcinomatosis-induced bowel obstruction. *Treatment*- NR	From gastrostomy placement	"average" 83.7 days (range: 20–338 days)	All patients had the PEG tube functioning well after the procedure with immediate relief of obstructive symptoms of persistent nausea and vomiting.	NR

Zucchi 2016 Retrospective cohort study Italy	The aim of this study is to examine, in a large single-centre cohort of 158 successive patients with MBO and abdominal carcinomatosis from advanced gynaecological and gastroenteric cancer, the efficacy and outcomes of PEG.	158 Age- NR Sex- NR 100%	*Diagnosis* • Colon carcinoma n= 13 • Gastric carcinoma n= 7 • Gallbladder carcinoma n= 2 • Breast carcinoma n= 2 • Pancreas carcinoma n= 2 • Ovarian carcinoma n= 96 • Portio carcinoma n= 6 • Endometrial carcinoma n= 8 • Uterine sarcoma n= 6 Malignant small bowel obstruction from abdominal-pelvic carcinomatosis *Treatment* All patients had at least one previous gastrointestinal surgical procedure (19.7 % had one surgical procedure, 42.2 % had two, 28.1 % had three, 7.7 % had four, 2.1 % had five)	From gastrostomy placement	Median 57 days (Range 4-472)	110 (77.4 %) experienced complete relief from nausea and vomiting and were able to resume oral liquids and small amounts of soft food intake for a median of 57 days with self-reported satisfaction. Twelve patients (8.4 %) had only nausea, while 20 (14 %) had persistent vomiting.	25 patients had an SDS score properly evaluated. Sixteen (64 %) improved (41 vs 32.6, pre- and post-PEG median scores, respectively, $p < 0.01$), two (8 %) at a further assessment showed the same scores as at baseline, and seven (28 %) had non-significant worsening (30.85 vs 36.14, p=0.18) of QoL. Of the 16 patients who showed an improvement in the QoL, nine reported an improvement of symptoms

							at physical (19.6 vs 14.75, p < 0.01), psychological (10.1 vs 7.3, p < 0.05), and somatopsychic levels (11.25 vs 9.2, p < 0.05). Regarding diet tolerance, all were able to resume oral liquid and small amounts of soft food intake. Of the remaining seven patients, one reported improvement at the physical level, three at the psychological level, and three at the somatopsychic level. The worsening of global QoL was determined by

							the persistence of the physical symptoms (14.57 vs 20, $p < 0.05$) while psychological and somatopsychic levels remained stable. Symptom Distress Scale (SDS) of McCorkle and Young (1978)

Health Service Utilisation and Place of Death

Study	Discharge status	Place of death			Length of stay	Readmissions/ hospitalisations	ICU admissions
Parenteral Nutrition							
August 1991						Three patients readmitted to evaluate complications possibly related to HPN.	
Bond 2019					Follow a series of improvement measure length of stay was reduced from 29.4 days to 10.1 days		
Brard 2006			TPN n= 28	No TPN N = 27			
		Home	11 (39%)	10 (37%)			
		Hospital	9 (32%)	7 (26%)			
		Hospice	8 (29%)	10 (37%)			
Chouhan 2016						Sixty-three (76.8%) patients required hospitalization after the initiation of systemic chemotherapy and TPN. The median number of hospitalizations was 2 (range, 1–11), and the median time spent hospitalized was 26.5 days (range, 4–167 days). On average, patients spent 38% (range, 1–100%) of their remaining lives in the hospital.	23 of those hospitalised patients admitted to the intensive care unit.
Duerksen 2004	Five of nine were discharged home.					One patient had five admissions.	

Dzierianowski 2021				Median 0 (range 0-13)	
Keane 2018		Most patients passed away in their homes or hospice (77.9%)			
King 1993				124 hospitalisations occurred during HPN. Thirty-seven admissions were for cancer therapy, 76 were for disease complications, and 11 were for HPN-related complications. Mean number of admissions was 2.0, median was 1, with a range of 0-11. Twenty-six percent of HPN patients had no admissions.	
Patel 2021			Median length of stay was 13 days, with greater lenth of stay in those referred for PN than those who were not (28 vs. 9 day, P= 0.0001)	The median number of readmissions was 1 (range 1-12).	Median number of ICU admission was 0
Palliative Venting Gastrostomy					
Adelson 1993		1 patient died in hospital on supportive care.			
Brooksbank 2002	Following insertion of the gastrostomy, 20 patients could be discharged home. Four other patients were transferred to country hospitals to	Six patients died at home and two patients were readmitted for the final few hours of life.			

	continue care nearer to home.				
Cannizarro 1995		Four in hospital			
Cunningham 1995	Twelve (60%) patients returned home for terminal care for 3 to 173 days (mean 70)				
Dittrich 2017	44 patients (59%) were discharged (home 36 patients, inpatient hospice 5, nursing facility 3)	Hospital n= 46 Home n= 23 Inpatient hospice n= 6	Median length of stay was 8.5 days (range 1–28)	Readmission rate was 48% (21/44 patients, range 1–5 readmissions	
Diver 2013				48 women (42%) were readmitted to the hospital at least once after GT placement due to GT related events	
Gauvin 2021	•Home n= 22 •Rehabilitation/SNF n= 7 •Hospice n= 25				
Goldberg 2021	Hospice enrolment Yes n= 95 No n= 22	Discharge status Alive n= 117 Dead n= 8	Length of stay for those discharged alive, days, median 10.0 (range 0.0-38.0)		
Issaka 2014				Four patients were re-admitted for recurrent symptoms due to VPEG tube dysfunction caused by clogging, and all were successfully replaced. Seven patients (7.9 %) were re-admitted for obstructive	

				symptoms despite a functioning VPEG tube.	
Jolicouer 2003	Fifty-eight per cent were discharged home with a primary caregiver. A quarter of patients were discharged to a hospice. Thirteen per cent died in hospital within 26 days of being admitted for their bowel obstruction and one patient was transferred to a community hospital close to home.	Thirteen per cent died in hospital		Of the 20 patients discharged from the acute care setting, 30% (n=6) required re-admission post-PEG insertion. A total of 20 readmissions were required, 70% did not require re-admission. The first re-admission occurred on average within 21.7 days of the patient being discharged (range from five to 60 days).	
Lilley 2018	Hospice enrolled n = 190 (76.4%)	Death in hospital n= 34 (13.8%)			ICU Care n= 32 (12.8%)
Merchant 2020		Death in hospital- 67/135	Median length of stay 23 days (IQR: 13-37)	Patient readmissions for MBO- 16/135 (11.9%)	
Pothuri 2005		Seventy-five (85%) of 88 patients died at home or under hospice care.	Five patients were able to leave the hospital the day of PEG tube placement, and 88 remained in the hospital for a mean stay of 6.9 days after the procedure.		

Rath 2013	71.7% were discharged home; 9.4% to an inpatient hospice facility, 15.1% to a nursing facility, and there were two inpatient deaths. Sixteen patients (30.2%) opted for hospice services	Two inpatient deaths	The median length of stay prior to placement of PDT was 6 days (range 1–27).		
Scheidbach 1999	83% discharged to home after PEG/PEJ (not stated where they died), 4 died in hospital.	Four hospital deaths	Average stay after PEG/PEJ placement was 6 days, range 3 - 31 days - except for 4 patients who could not be discharged secondary to disability - all died in hospital within days (up to 4 weeks) after treatment.		
Teriaky 2012		3 at home, 4 in hospital (3 of which after re-admission)		4 (67%) patients requiring re-admission for end stage palliation in hospital. The average length of time spent at home prior to readmission for in-hospital palliation was 126 days (range 7-467 days)	
Zucchi 2016	Out of 142 patients, 116 (81.6 %) were discharged	Twenty-six (18.3 %) out of 142 deaths occurred during the hospital stay because of disease progression	The median postoperative hospital stay		

			was 9 days (range 3–60).		

Qualitative synthesis themes

Theme	**Sub-theme**	**Codes**	**Quotations**
Theme one			
A stark decision- Do or Die	No alterative Decision has been made	Life or death Take it or leave it Perception of decision making Lifeline	"If I don't have the [HPN], I won't be here. There's no other way, is there?" (69) It's either die with food or [HPN] for the rest of your days and I'd sooner live and be on [HPN]" (69) No, why would I do that?" Asked about stopping HPN (69) "when I get to the point where I've got to say, oh, enough is enough, it won't matter then, but until that point comes then I just have to fight, keep going" (69) "there was no choice really, it was one of those take it or leave it, they didn't say that, but it's a take it or leave it, isn't it?" (73) "Well, to me it was a no option thing. I don't think they could have done anything else, bar starve me . . . if that's what's keeping me alive, it's what I have to have isn't it. So I don't think [there was] a decision as such, if there was no other . . . if I can't eat, it will be next best thing" (73) "Hobson's choice" (73)

			"Certainly yes, I mean what's the alternative…you just have to go with what the doctors recommend, I think. (75)
Theme two			
Realities of the intervention.	Benefits	Improved quantity and quality of life Valuing activities of daily living Increased energy/strength Symptoms	"spending time with family when you get to, like, my stage, is the most important for everybody" (69) "it's given me, yes, more energy" (69) "I think I've put a little bit of weight on" (69) "It's keeping her alive really. That's the big advantage." (Husband). (69) "it's going to help her do what she wants to do" (Husband). (69) "I'm looking forward to her being able to come out of hospital and go home and have the [HPN] at home and, sort of, have some sort of normality to life" (Daughter) (69) "Well they explained that 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. (75) "I hated that up my nose (NGT) it was so uncomfortable. It hurt me…it was horrible and uncomfortable in my throat, but this (referring to her PVG tube) isn't uncomfortable. (75)
	Burdens	Hospitalising home Role of carers Complexity of treatment Loss of normality Emotional loss Lack of information	"initially when this was being discussed with us ... I thought it was probably less medical than what it is" (Daughter). (69) "It wasn't as easy as it was made out to be" (69)

		Recommendations from HCP	"It just becomes a way of life really, you know what I mean, this is how your day goes and this is what it is. A nurse comes and takes it off in a morning and then a nurse comes at night and puts it back on" (Belinda). (69) "I've tried creeping, 'cause I don't want to wake him up" (Penny). "I'm awake most of the night listening for her, but she tells me not to help her" (Husband). (69) "I am physically falling to bits" (Daughter). (69) "what you sign on for when you get married" (Husband) (at the end of the second interview, he reported feeling like a "prisoner") (69) "It would be wonderful if I could have even 5 h sleep without a break" (Marilyn). (69) "It's difficult, yeah, especially going upstairs, be- cause I've not got much energy, so usually my husband ... has to take it for me" (69) "when I go in the shower and everything, I can ... take both tubes off, and I'm a different person" (69) "a ball and chain" (Husband). (69) "I've done things for him. He can do things for me" (69) "as for going out and taking a contract on or something. It's just not feasible" (Husband). (69) "(are you able to walk up and down the stairs?) …not when carrying my bags (referring to her PVG, PN and syringe pump), but X (partner) carries those either behind or in front of me." (75)

			"My husband has been in a lot of discomfort, it has been leaking all the time, he's being changed numerous times a day, the beds have to be changed and now his skin is all sore." (75) "You can smell it though, even if it's not leaking. I feel like…it smells like sewage, it's not faecal, it's worse than that, it's a sewage smell and I feel like I can smell it all the time and anyone who is anywhere near me can smell it. It is making me quite paranoid, I am constantly asking my husband if he can smell it…I don't get embarrassed too easily, but I do find that quite difficult to deal with)" (75) when I got down to radiology, Dr X (Consultant IR) came and explained it all to me and I was even more anxious then because I sort of then understood what was happening… (not given any written information pre-PVG)" (75) "(Referring to ward nurses): …one nurse who was giving it a clean said, you don't rotate this one…that other nurse, she said something about I'll rotate it and I said oh well I've been told not to rotate mine." (75)