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Special Issue: Prehab to Rehab: Living With and Beyond Cancer

Guest Editors: Sorrel Burden, Clare Shaw and Rachael Barlow

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Special Issue: Prehab to Rehab: Living With and Beyond Cancer
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ORIGINAL ARTICLE

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Health service nutrition practices and associations with clinical outcomes in patients undergoing resection for upper gastrointestinal cancer: Results from the multi-centre NOURISH point prevalence study

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Abstract

Background: The present study aimed to investigate health service nutrition practices of sites providing care to patients undergoing surgery for upper gastrointestinal cancer within Australia, including the provision of perioperative nutrition support services and outpatient clinics, as well as the use of evidence-based nutrition care pathways/protocols. Secondary aims were to investigate associations between the use of a nutrition care pathway/protocol and patient outcomes.

Methods: Principal investigator dietitians for the sites ($n = 27$) participating in the NOURISH point prevalence study participated in a purpose-built site-specific survey regarding perioperative nutrition practices and protocols. Data from the 200 patients who participated in the study (including malnutrition prevalence, preoperative weight loss and receipt of dietetics intervention, intraoperative feeding tube insertions, provision of nutrition support day 1 post surgery, length of stay, and complications) were investigated using multivariate analysis to determine associations with the sites' use of a nutrition care pathway/protocol.

Results: The majority of sites (>92%) reported having dietetics services available in chemotherapy/radiotherapy. Eighty-five percent of sites reported having some form of outpatient clinic service; however, a routine service was only available at 26% of sites preoperatively and 37% postoperatively. Most preoperative services were embedded into surgical/oncology clinics (70%); however, this was reported for only 44% of postoperative clinics. Only 44% had a nutrition care pathway/protocol in place. The use of a nutrition care pathway/protocol was associated with lower rates of malnutrition, as well as higher rates of preoperative dietetics intervention, intraoperative feeding tube insertions, and European Society of Clinical Nutrition and Metabolism (ESPEN) guideline compliant care day 1 post surgery.

Conclusions: The results of the present study demonstrate varied perioperative outpatient nutrition services in this high-risk patient group. The use of

nutrition care pathways and protocols was associated with improved patient outcomes.

KEYWORDS

dietitian, gastrointestinal cancer, malnutrition, nutrition care pathway, outpatient

Key points

- Perioperative nutrition support is strongly recommended for patients undergoing surgery for upper gastrointestinal cancer. However, the level of perioperative nutrition services in Australia including the use of outpatient clinics and nutrition care pathways is currently unknown.
- Data from the 27 hospitals, and the 200 patients who participated in the NOURISH point prevalence study was analysed to report on health service nutrition practices in UGI cancer resection, and associations with patient outcomes.
- Results demonstrated inconsistent nutrition support practices, with 44% of sites having an evidence-based nutrition care pathway/protocol in place.
- The use of a nutrition care pathway/protocol was associated with lower rates of malnutrition, and higher rates of preoperative dietetics intervention, intraoperative feeding tube insertions and ESPEN guideline compliant nutrition care day one post surgery.

INTRODUCTION

This Nutritional *O*utcomes of patients *U*ndergoing *R*esection for upper gastro*I*ntestinal cancer in Au*S*tralian *H*ospitals study (the NOURISH point prevalence study) reported that malnutrition prevalence at time of upper gastrointestinal (UGI) cancer surgery was 42%, with 49% of patients reporting clinically significant weight loss in 6 months.[1] Because malnutrition and weight loss are associated with increased morbidity and mortality in patients with cancer,[2] early identification and treatment is essential to optimise patients' outcomes. However, significant inadequacies and variations in perioperative nutrition care were demonstrated in patients participating in NOURISH, with only 60% reporting seeing a dietitian prior to surgery, and only 50% reporting being prescribed nutrition support prior to surgery.[3]

The results of the NOURISH point prevalence study demonstrate a clear need for improved identification and treatment of malnutrition in this high-risk patient group. Strategies to improve perioperative care include the funding of dedicated outpatient clinics to enable early access to nutrition assessment, intervention and regular monitoring.[4] Dietitians should be considered essential members of the multi-disciplinary team, aiming to ensure that nutritional management is addressed appropriately alongside medical care.[5] Several studies have also demonstrated that implementation of structured nutrition care pathways and protocols can improve adherence to evidence-based nutrition guidelines in several oncology populations, including oesophageal cancer,[6] lower gastrointestinal surgery,[7] haematology[8] and lung cancer.[9] The European Society of Clinical Nutrition and Metabolism (ESPEN) surgical guidelines recommend that standard operating procedures/protocols should be utilised to ensure effective provision of nutrition support post surgery.[10] Furthermore, the Enhanced Recovery After Surgery (ERAS) guidelines outline several nutritional recommendations that should be embedded into surgical pathways, including nutrition assessment and provision of nutrition support prior to surgery, as well as early commencement of oral or enteral nutrition postoperatively.[11]

However, it is currently unknown whether tertiary institutions conducting curative UGI cancer surgery in Australia provide dedicated perioperative nutrition services such as outpatient clinics and what level of service is provided. Furthermore, it is also unknown whether these institutions provide care according to nutrition care pathways or protocols, and whether this is associated with patient outcomes including provision of evidence-based perioperative nutrition care. Therefore, the primary aim of the present study was to investigate health service nutrition practices of sites participating in the NOURISH point prevalence study,[12] including the provision of perioperative nutrition support services and outpatient clinics, as well as the use of evidence-based nutrition care pathways and protocols. Its secondary aims were to investigate associations between the use of an evidence-based nutrition care pathway/protocol and patient level outcomes, including malnutrition prevalence, preoperative weight loss, rates of dietetics intervention and nutrition support, intraoperative feeding tube insertions, ESPEN guideline compliant postoperative nutrition care, and surgical outcomes (length of stay (LOS) and complications).

METHODS

Study design and population

Twenty-seven tertiary hospitals from six of eight Australian states/territories participated in the NOURISH point prevalence study. Prior to beginning patient recruitment for the study, each site's principal investigator dietitian completed a purpose-built survey regarding dietetics practices for the management of UGI surgical oncology patients at their site (see Supplementary File 1). Figure 1 outlines the data utilised in this substudy of the NOURISH point prevalence study.

Site-specific dietetics practices questionnaire

The purpose-built survey was developed by the study's investigators, which included clinical and academic dietitians, as well as an academic surgeon. The survey was piloted on two UGI dietitians to ensure clarity of the survey questions and instructions. The survey was not formally validated because it contained questions that required factual answers only. The survey comprised 42 questions pertaining to: (1) dietitian attendance at the weekly surgical oncology multidisciplinary meeting (MDM); (2) site specific perioperative dietetics services (type of services available before/during/after surgical admission, referral procedures, time allocation per week); and (3) the use of evidence-based nutrition care pathways or protocols (presence of ERAS and nutrition aspects included, presence of nutrition care pathways/protocol and timepoints of commencement/completion of pathway, areas of nutritional management outlined, year of development, and frequency of review). Each site provided identifiable site data to be able to perform data linkage of the site's responses with the site's patient data.

Patient recruitment and data collection

Full descriptions of methodology, inclusion and exclusion criteria, as well as a detailed description of the study's patient population, are available elsewhere.[1,12] Patients (≥18 years) were eligible to participate if they had undergone curative intent oesophageal, gastric or pancreatic surgery for UGI cancer, were able to consent to participation by English language communication or with the presence of an interpreter, and had received an assessment of nutritional status with Subjective Global Assessment (SGA) by a dietitian within 7 days of surgery. Patients were ineligible if they were unaware of their diagnosis or unable to participate in SGA, or if their surgery was palliative or non-oncological.

Baseline data included in this substudy related to age, sex, tumour stage and nutritional status.[12] The SGA was performed by trained dietitians to determine nutritional status (malnourished [SGA B/C] or well nourished [SGA A]) within 7 days of surgery[13] because most sites were not funded to perform nutritional assessments prior to surgery. All sites' investigator dietitians performing the SGA utilised a standard protocol and undertook training prior to commencement of the study, as described in the published protocol.[12] Patients' weight was measured using calibrated scales or was patient reported (patients were asked to recall their weight the week before surgery if they could not be weighed at the time of surgery). Patients were also asked to recall information regarding preoperative weights at 2 weeks, 1 month, 3 months and 6 months, with recall data cross-checked where possible from the medical records. Preoperative weight loss was calculated, with clinically significant weight loss set as ≥5% in 6 months prior to surgery.[14] The insertion of intraoperative feeding tubes, nil by mouth or fluid 'diet codes' (clear fluids, free fluids) and the use of enteral nutrition, parenteral nutrition or oral nutrition support day 1 post surgery were recorded by dietitians, to determine whether nutrition intervention provided then was compliant with ESPEN recommendations of early nutrition support.[10] Length of stay (in days) post surgery was calculated from the medical record. Surgical complications were recorded as documented by the medical team in the patient's medical entry (sepsis, anastomotic leak, pancreatic fistula, pneumonia/respiratory tract infection, pneumothorax, pressure injury, wound infection, return to theatre, abdominal collection, ileus, chyle leak, gastroparesis and pleural effusion). For analysis, based on the spread of data, complications were reclassified into 'no complication' or '≥1 complication'.[1]

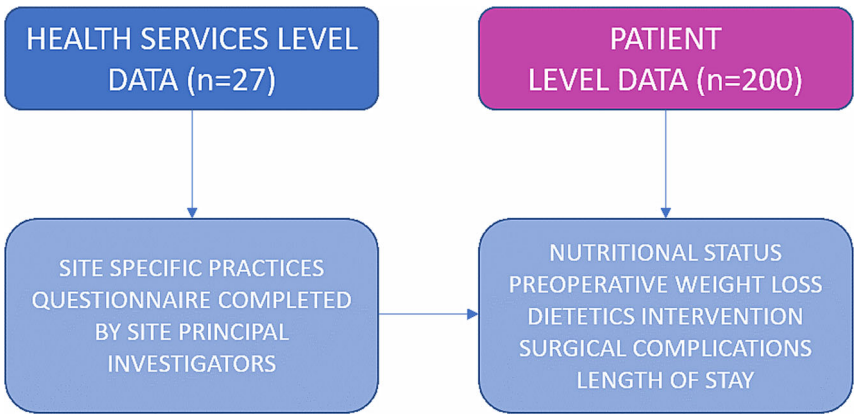

FIGURE 1 Data utilised in the present study

Statistical analysis

A descriptive analysis was undertaken including frequencies and percentages. Multivariate regression models adjusting for age, sex, malnutrition, ≥5% weight loss in 6 months, surgical procedure (gastrectomy, pancreatectomy, oesophagectomy), neoadjuvant therapy and tumour stage were utilised to determine associations between the use of a preoperative nutrition care pathway and malnutrition at time of surgery, receipt of preoperative dietetics intervention, preoperative nutrition support, and 1- and 2-month preoperative weight loss. Multivariate regression models adjusting for age, sex, malnutrition, ≥5% weight loss in 6 months, use of ERAS protocol within surgical unit, surgical procedure and tumour stage determined associations between the use of a nutrition care pathway and postoperative outcomes. These associations included LOS, surgical complications, intraoperative feeding tube insertions and adherence to ESPEN guidelines for postoperative initial nutrition management. Linear regression was utilised for continuous outcomes, whereas logistic regression was used for binary outcomes. $p < 0.05$ (two-tailed) was considered statistically significant. Statistical analyses were conducted using Stata/IC, version 16.0 (StataCorp LLC).

RESULTS

Site characteristics

Of the 27 hospitals that participated in the study, 92.6% ($n = 25$) were publicly funded and 7.4% ($n = 2$) were privately funded. The majority (92.6%, $n = 25$) were located in a metropolitan area and 7.4% ($n = 2$) were regional. The majority of sites (77.8%, $n = 21$) performed an estimated annual UGI surgical caseload of >30 surgeries per annum, and there were six sites (22.2%) with an annual caseload of 20–30 surgeries per annum.

Patient characteristics

Of the 240 patients screened, 200 consented and participated in the study (all of whom are included in this substudy). Table 1 outlines the baseline characteristics of the patient cohort.

Preoperative and postoperative nutrition practices

Regular dietitian attendance at the surgical oncology MDM was reported in 59.3% ($n = 16$) sites and 22.2% ($n = 6$) reported that the dietitian 'sometimes' attended. Five health services (18.5%) reported no dietetic representation at the MDM. Table 2 describes the preoperative and postoperative nutrition practices of sites in terms of oncology and outpatient clinic services provided. Sites consistently reported higher levels of service in the postoperative setting than in the preoperative setting.

TABLE 1 Patient baseline characteristics ($n = 200$)

Variable	*n*	%
Age (years), mean (SD)[a]	67 (10)	
Sex (*n*, %)		
Male	117	58.0%
Female	83	42.0%
Surgery type (*n*, %)		
Oesophagectomy	66	33.0%
Gastrectomy	50	25.0%
Pancreatectomy	84	42.0%
Tumour stage (*n*, %)		
T0	15	7.5%
T1	44	22.0%
T2	49	24.5%
T3	63	31.5%
T4	14	7.0%
TX	2	1.0%
Unknown/unassessed	13	6.5%
Nutritional status (*n*, %)		
Well-nourished	116	58.0%
Malnourished	84	42.0%

[a]Continuous data are expressed as the mean (SD).

Nutrition pathways and protocols

Forty-four percent of sites reported having an ERAS protocol in place in their UGI surgical unit; however, nutrition components of ERAS were not consistently utilised at these sites (Table 3). Similarly, 44% reported having a formal nutrition care pathway or protocol, with the majority (58.3%) of pathways commencing at initial cancer diagnosis and treatment planning. Figure 2 demonstrates the components of nutritional management outlined in the care pathways at these 12 sites.

Associations between nutrition care pathways and protocols, and patient outcomes

Of the 200 patients who participated in the point prevalence study, 86 (43%) received dietetics care at a site that had a nutrition care pathway which commenced in the preoperative period, whereas 97 (49%) received

TABLE 2 Preoperative and postoperative nutrition practices

Variable	Preoperative setting		Postoperative setting	
	n	%	*n*	%
Dietetics services in chemotherapy[a]				
Routine service	6	23.1%	8	30.8%
Processes in place to see high risk patients	14	53.8%	14	53.8%
Referrals only	4	15.4%	4	15.4%
No service	2	7.7%	0	0.0%
Dietetics services in radiotherapy[b]				
Routine service	9	39.1%	10	43.5%
Processes in place to see high risk patients	7	30.4%	8	34.8%
Referrals only	6	26.1%	5	21.7%
No service	1	4.3%	0	0.0%
Outpatient clinic				
Routine service for all UGI surgical oncology patients	7	25.9%	10	37.0%
Processes in place to see high risk patients	3	11.1%	11	40.8%
Referrals only	13	48.2%	2	7.4%
No service	4	14.8%	4	14.8%
Location of outpatient clinic[c]				
Clinic embedded in surgical/oncology or preadmission clinic	16	21.7%	10	43.5%
Dietetics stand-alone clinic	5	69.6%	12	52.2%
No set location, ad hoc or phonecalls	2	8.7%	1	4.3%
Main referral procedure to nutrition service[c]				
Referrals by other MDT members	16	69.6%	1	4.3%
Dietitian screens patients	3	12.0%	21	91.3%
Screening by dietitians andreferrals from MDT members	2	8.7%	0	0.0%
No set referral process	2	8.7%	1	4.3%
Hours per week for UGI outpatient service[c]				
<1 h per week	12	52.2%	4	17.4%
1–2 h per week	9	39.1%	13	56.5%
3–4 h per week	2	8.7%	5	21.7%
>6 h per week	0	0.0%	1	4.3%
Referrals to other outpatient dietetics services postoperatively[d]				
Private dietitians	NA	NA	5	18.5%
Community health service dietitians	NA	NA	9	33.3%
Other health service	NA	NA	8	29.6%
Rarely refer to other services	NA	NA	12	44.4%

Abbreviations: NA, not available; MDT, multi-disciplinary team; UGI, upper gastrointestinal.

[a]Presented as a proportion of sites who had chemotherapy services at their site ($n = 26$).

[b]Presented as a proportion of sites who had radiotherapy services at their site ($n = 23$).

[c]Presented as a proportion of sites who had an outpatient service for UGI surgical oncology patients at their site ($n = 23$).

[d]Participants could select multiple response options.

TABLE 3 Nutrition pathways and protocols

Variable	*n*	%
ERAS protocols in place		
Yes	12	44.4%
No	15	55.6%
Nutrition components of ERAS[a]		
Immunonutrition	5	41.7%
Carbohydrate loading	10	83.3%
Preoperative nutrition advice	4	33.3%
Formal nutrition care pathway or protocols		
Yes	12	44.4%
No	14	51.9%
Unsure	1	3.7%
Timepoint that pathway/protocol commences[b]		
Initial cancer diagnosis and treatment planning	7	58.3%
Preadmission clinic	2	16.7%
At the start of the surgical admission	3	25.0%
Timepoint that pathway/protocol is completed[b]		
At the end of the surgical admission	7	58.3%
1–3 months after surgery	2	16.7%
3–6 months after surgery	2	16.7%
> 12 months after surgery	1	8.3%
Duration of pathway being in place[b]		
< 2 years	2	16.7%
<5 years	6	50.0%
5–10 years	3	25.0%
> 10 years	1	8.3%
Frequency of pathway review[b]		
Never	1	8.3%
Annually	1	8.3%
Every 2 years	2	16.7%
> Every 2 years	3	25.0%
When required	4	33.3%
Unsure	1	8.3%

Abbreviation: ERAS, Enhanced Recovery After Surgery.

[a]Presented as a proportion of sites who had ERAS protocols ($n = 12$), participants could select multiple options.

[b]Presented as a proportion of sites who had nutrition care pathways/protocols in place ($n = 12$).

care at a site that had a nutrition care pathway including the postoperative period (surgical inpatient admission until surgical discharge). Table 4 presents patient level data assessed using multivariate regression analysis to determine the association of receiving care at a site with a nutrition care pathway and patient outcomes including malnutrition, preoperative weight loss, receipt of preoperative dietetics intervention/nutrition support, feeding tube insertions and receipt of ESPEN guideline compliant postoperative nutrition care. Patients who received care at a site with a preoperative care pathway were less likely to be malnourished on admission for surgery ($p = 0.048$) and more likely to receive preoperative dietetics intervention ($p = 0.036$). A postoperative nutrition care pathway was associated with a higher likelihood of receiving an intraoperative feeding tube insertion ($p = 0.018$) and a higher likelihood of receiving care that was compliant with ESPEN guidelines ($p < 0.05$ for all three guideline recommendations assessed).

DISCUSSION

Perioperative nutrition services

Over 80% of sites in the present study reported some form of perioperative dietetics service available to patients undergoing UGI cancer surgery. However, less than half of sites reported a routine outpatient service for this high-risk population, indicating that service and referral procedures still require improvement. Platek et al.[15] conducted a study of Comprehensive Cancer Centres in the USA and found that, although nutrition services were available, 77% reported that services for patients with gastrointestinal cancer were referral/consult-based only. Prior research demonstrates that malnutrition risk may not always be appropriately identified in oncology patients and referrals to dietitians by other healthcare professionals may be missed or delayed.[16,17] A recent survey of surgeons demonstrated that 44% did not arrange any form of preoperative nutrition consultation for patients undergoing pancreaticoduodenectomy.[18] Interestingly, in the present study, almost half of sites reported a referral-only based outpatient service preoperatively; however, this dropped to less than 10% for the postoperative setting with most sites reporting a routine service or procedures in place to see high-risk patients. This could be a result of dietitians being able to self-refer patients to postoperative services from the surgical admission (91% vs. 12% preoperatively) and increased funding of postoperative services. Historically, there has been a stronger focus on 'rehabilitation' than 'prehabilitation' in elective abdominal surgery,[19] and the majority of sites reported a higher number of hours per week allocated to postoperative dietetics services than for the preoperative setting. In a recent study of multi-disciplinary Australian UGI clinicians, 77% of respondents felt that lack of funding for dietitians was a barrier for providing optimal outpatient nutrition support services. Given the strong recommendations for perioperative nutrition assessment and intervention,[10] it

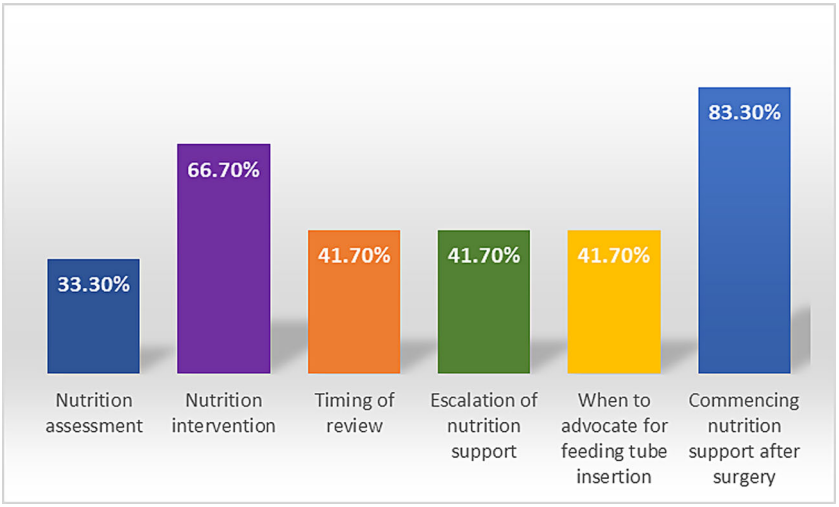

FIGURE 2 Components of nutrition management outlined in the nutrition care pathways of sites ($n = 12$)

is concerning that 15% of sites in the present study reported no outpatient services before or after surgery. However overall, the results of the present study are more positive compared to the results of previously conducted surveys of Australian UGI dietitians over 7–10 years ago, which estimated significantly lower outpatient service provision to this population.[4,20]

We have previously demonstrated that receiving neoadjuvant therapy was associated with greater likelihood of receiving preoperative dietetics intervention,[3] which is supported by the results of this study demonstrating that the vast majority of sites had dietetics services available in the chemo/radiotherapy settings. However, only 23% and 39% of sites reported having a routine service for the preoperative chemotherapy and radiotherapy settings, respectively, with 31% and 43% for the postoperative chemotherapy and radiotherapy settings. The ESPEN recommendations outline that patients undergoing oncological treatment for UGI cancers are considered at high risk, and that all patients should receive dietetics assessment.[21]

Management of nutritional status should be performed in parallel with the oncology pathway and should be performed collaboratively between members of the multi-disciplinary team.[22] The Australian Optimal Care Pathways for UGI cancers outline the dietitian as an essential member of the multi-disciplinary team who should be present at surgical oncology MDM meetings.[5] Over 50% of sites reported regular dietitian attendance at these meetings, whereas 22% reported irregular attendance and 19% reported no attendance. In a large European survey of oncology surgeons, only one-third of respondents reported that dietitians/nutritionists attend the MDM.[23] There are several advantages of dietetics care being provided in a multi-disciplinary outpatient clinic setting. Patients often require medications for symptom control, which require prescription by a medical practitioner. Furthermore, collaborative discussions regarding early screening of patients, escalation of nutrition support and insertion of enteral feeding tubes can facilitate more timely and proactive care.[22] Seventy percent of preoperative dietetics services were co-located within a surgical/oncology or preadmission clinic, which is encouraging because patients can present with significant nutritional issues at diagnosis that may require multidisciplinary management.[24,25] However, this was the case for only 43% of postoperative clinics. Considering that many patients report significant weight loss and ongoing symptoms after surgery,[26] it is surprising that multidisciplinary nutrition care is not continued postoperatively at some sites and this could be seen as an area for service improvement.

Nutrition care pathways and protocols

Less than half of sites in the present study reported having any form of nutrition pathway or protocol in place for nutrition in UGI cancer surgery. The study by Platek et al.[15] also found that 46% of participating centres reported utilising a standard nutrition protocol for gastrointestinal cancer outpatients. In terms of the impact on patient outcomes in the present study, a 50% risk reduction of malnutrition at the time of surgery was demonstrated for patients who received care under a preoperative nutrition care pathway/protocol, which may be because patients were also more likely to receive preoperative dietetics intervention. Although not statistically significant, patients who received care under a nutrition care pathway also lost less weight in the immediate preoperative period than those who did not. This is not surprising given that we have previously reported that receiving ≥ 3 preoperative dietetics appointments was associated with lower percentage weight loss because a nutrition care pathway can create a structured approach to nutrition reviews enabling ongoing monitoring and adjustment of intervention.[3] Previous studies have also demonstrated a reduction in malnutrition rates and

weight loss when a nutrition care pathway was implemented in an oncology population.[27,28] Receiving care under a pathway/protocol was not associated with receiving preoperative nutrition support, and this could be a result of other health care professionals administering nutrition support such as oral nutrition supplements without the involvement of a dietitian,[3] particularly at sites with limited dietetics services.

Improved compliance with ESPEN guidelines for early oral intake and nutrition support were demonstrated at sites where dietitians implemented nutrition care pathways/protocols. This is not surprising given that 83% of the 12 sites reported that their pathway outlined standardised guidelines for commencing nutrition support after surgery. Standardised protocols have been shown to improve nutrition support prescription in other clinical areas, including the intensive care setting.[29] Given the strong evidence for ERAS protocols in major abdominal surgery,[11] it is surprising that only 44% of sites had ERAS protocols implemented within their surgical unit and, of those, only 33% included preoperative nutrition advice. Further quality improvement is required to embed nutrition protocols within existing ERAS protocols.

TABLE 4 Associations between nutrition care pathways and protocols and patient outcomes

Variable from patient NOURISH patient level data	No nutrition care pathway	Nutrition care pathway	Multivariate analysis OR (95% CI)	*p*-value
Malnutrition at time of surgery[a]				
No	55 (53.4)	61 (62.9)		
Yes	48 (46.6)	36 (37.1)	0.5 (0.3, 0.9)	**0.048**
Preoperative dietetics intervention[a]				
No	49 (48.5)	29 (30.2)		
Yes	52 (51.5)	67 (69.8)	2.2 (1.1, 4.5)	**0.036**
Preoperative nutrition support[a]				
No	53 (52.0)	45 (47.4)		
Yes	49 (48.0)	50 (52.6)	0.9 (0.5, 1.8)	0.878
1 month weight loss[a,b]	2.4 (3.2)	1.9 (2.5)	−0.4 (−1, 0.8)	0.554
2 weeks weight loss[a,b]	1.2 (2.1)	1.1 (2.1)	−0.2 (−1.1, 0.7)	0.659
Length of stay[c,d]	14 (8.8, 18)	10 (8,15)	2.5 (−1.1, 6.2)	0.170
Complications[c]				
No	64 (62.1)	51 (52.6)		
Yes	39 (37.9)	46 (47.4)	1.4 (0.7, 2.3)	0.366
Intraoperative feeding tube insertion[c]				
No	64 (64.0)	40 (42.1)		
Yes	36 (36.0)	55 (57.9)	2.9 (1.2, 6.9)	**0.018**
ESPEN guideline followed day 1 post surgery[c,e]				
No	66 (64.1)	38 (39.2)		
Yes	37 (35.9)	59 (60.8)	3.5 (1.6, 7.9)	**0.002**
EN/PN started if NBM day 1 post surgery[c]				
No	45 (59.2)	30 (39.0)		
Yes	31 (40.8)	47 (61.0)	3.5 (1.3, 9.3)	**0.012**
ONS/EN/PN started day 1 post surgery[c]				
No	65 (63.1)	36 (37.1)		
Yes	38 (36.9)	61 (62.9)	4.0 (1.8, 9.0)	**0.001**

Note: Bold *p* values indicate statistical significance.

Abbreviations: CF, clear fluids; CI, confidence interval; EN, enteral nutrition; FF, free fluids; NBM, nil by mouth; ONS, oral nutrition support; OR, odds ratio; PN, parenteral nutrition.

[a]This analysis assessed data from sites who had a preoperative nutrition care pathway in place versus those sites that did not. Each variable adjusted for age, sex, tumour stage, surgery type, neoadjuvant therapy, presence of malnutrition and ≥5% weight loss in 6 months in multivariate regression models.

[b]Continuous data expressed as the mean (SD), multivariate regression coefficient.

[c]This analysis assessed data from sites who had a postoperative nutrition care pathway in place versus those sites that did not. Each variable adjusted for age, sex, tumour stage, surgery type, ERAS procedure in place in surgical unit, presence of malnutrition and ≥ 5% weight loss in 6 months in multivariate regression models.

[d]Continuous data expressed as the median (interquartile range), multivariate regression coefficient

[e]Early oral intake or EN/PN commenced day 1 post surgery according to ESPEN guidelines.

Implications for practice and future research

In high-risk settings such as UGI surgical oncology, preoperative nutrition screening and intervention should be a fundamental component of dietetics care. However, as demonstrated in the present study and the aforementioned studies, finite resources and competing priorities for these resources mean that this is not always the case. Nutrition care pathways and dedicated outpatient clinics require an investment of funding for dietitians, and this is largely considered to be a main reason why improved services have not been facilitated despite the evidence for early and sustained nutrition support in surgical oncology. However, given the healthcare costs associated with malnutrition, the reduction of malnutrition rates demonstrated presents a strong argument for a potential cost benefit of implementation. Findlay et al.[30] implemented

an evidence-based model of nutrition care for patients with head and neck cancer that resulted in improved nutrition care according to guideline recommendations, including early access to nutrition assessment and intervention. A cost saving of $121,000 AUD per annum was demonstrated, which was attributed to a reduction of unplanned hospital admissions.[30] Similar interventional studies in the UGI setting would be beneficial to demonstrate cost benefit savings and enable advocacy for resource allocation for preoperative services. Well-conducted randomised controlled trials would also assist in the development of UGI specific nutrition guidelines outlining the most optimal type, timing and frequency of care to be provided, enabling further standardisation of nutrition care across health services and settings.[4] These studies should include an analysis of barriers and enablers to implementation, aiming to ensure that evidence is directly translatable into clinical practice.

Strengths and limitations

The strengths of the present study include the detailed reporting of 'real world' nutrition services available to UGI surgical oncology patients across Australia, as well as the ability to investigate the impact of site-specific nutrition support practices with patient level outcomes. Although only participating NOURISH point prevalence study sites were included, they include representation from six of eight Australian states/territories. The results would likely be generalisable to other Australian and international health services, including the UK and Canada, where dietitians are actively involved as members of multidisciplinary oncology care. However, the results may not be generalisable to European health services, where nutrition models of care vary. To our knowledge, this is the first study to demonstrate improved adherence to evidence-based perioperative nutrition recommendations when nutrition care pathways are utilised in a large UGI surgical cohort. We also accounted for the use of ERAS protocols in the analysis, further demonstrating the benefits of nutrition protocols embedded into dietetics and surgical care. The self-reported nature of sites' practices by dietitians is a limitation; however, the survey was completed by principal investigator dietitians who were UGI leads and well placed to be able to report on UGI nutrition practices within their individual sites. Practices may have also changed at some sites during the course of patient recruitment, and adherence to nutrition care pathways was not assessed. Because of the low number of privately funded hospitals ($n = 2$), we were unable to investigate differences between private and public hospitals. Finally, the study was powered for malnutrition prevalence precision (the primary aim of the main study) and not for the outcomes analysed in this substudy which could influence the statistical significance of the results in this substudy.

CONCLUSIONS

The present study demonstrates that preoperative outpatient dietetics services in UGI cancer are varied and most sites do not provide a routine preoperative service to all UGI surgical oncology patients despite recommendations. Postoperative outpatient services were reported to have more streamlined referral systems and funding allocation to service high-risk patients than preoperative services. The use of nutrition care pathways and protocols was associated with lower rates of malnutrition, preoperative dietetics intervention and ESPEN guideline compliant postoperative nutrition care. Further research should be conducted in a randomised trial setting to provide strong evidence to form UGI specific nutrition guidelines.

AUTHOR CONTRIBUTIONS

Irene Deftereos is the coordinating investigator and conceptualised the study. Nicole Kiss, Justin M. C. Yeung, Elizabeth Isenring and Vanessa M. Carter contributed to the study conception and design. Irene Deftereos drafted and edited the study protocol and manuscript. Nicole Kiss, Justin M. C. Yeung, Vanessa M. Carter and Elizabeth Isenring assisted with the study protocol and edited the manuscript. Janan Arslan and Irene Deftereos performed the statistical analysis. Members of the NOURISH Point Prevalence Study Group provided feedback on the study protocol and manuscript, carried out the study recruitment and data collection. All authors have read and approved the final version of the manuscript submitted for publication.

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CONFLICTS OF INTEREST

Irene Deftereos has received a research grant from the Australian Society of Enteral and Parenteral Nutrition (AuSPEN), unrelated to the present study.

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ETHICS STATEMENT

Ethics approval was obtained from The Peter MacCallum Cancer Centre Ethics Committee (LNR/51107/PMCC-2019). Patient recruitment was conducted between 2 September 2019 and 30 May 2020 with data collection completed on 30 June 2020.

TRANSPARENCY DECLARATION

The authors affirm that this manuscript is an honest, accurate and transparent account of the study being reported. The authors affirm that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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ORIGINAL ARTICLE

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Implementation of a standardised perioperative nutrition care pathway in upper gastrointestinal cancer surgery: A multisite pilot study

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Abstract

Background: Perioperative nutrition support is recommended for patients undergoing upper gastrointestinal (UGI) cancer surgery; however, limited evidence exists regarding implementation of a nutrition care pathway in clinical practice. The aims of this pilot study were to determine whether implementation of a standardised perioperative nutrition pathway for patients undergoing UGI cancer surgery improves access to dietetics care, as well as to evaluate study feasibility, fidelity, resource requirements and effect on clinical outcomes.

Methods: Patients with newly diagnosed UGI cancer from four major metropolitan hospitals in Melbourne, planned for curative intent surgery, were included in the prospective pilot study ($n = 35$), with historical controls ($n = 35$) as standard care. Outcomes were dietetics care (dietetics contacts) nutritional status, hand grip strength, weight change, preoperative hospital admissions, complications and length of stay, recruitment feasibility, fidelity and adherence, and resource requirements. Continuous data were analysed using independent samples t test accounting for unequal variances or a Mann–Whitney U test. Dichotomous data were analysed using Fisher's exact test.

Results: The percentage of participants receiving preoperative dietetic intervention increased from 55% to 100% ($p < 0.001$). Mean ± SD dietetics contacts increased from 2.2 ± 3.7 to 5.9 ± 3.9 ($p < 0.001$). Non-statistically significant decreases in preoperative nutrition-related hospital admissions, and surgical complications were demonstrated in patients who underwent neoadjuvant therapy. Recruitment rate was 81%, and adherence to the nutrition pathway was high (> 70% for all stages of the pathway). The mean ± SD estimated resource requirement for the preoperative period was 3.7 ± 2.8 h per patient.

Conclusions: Implementation of this standardised nutrition pathway resulted in improved access to dietetics care. Recruitment feasibility and high fidelity to the intervention suggest that a larger study would be viable.

KEYWORDS

dietitian, gastrointestinal cancer, malnutrition, nutrition care pathway, nutrition support

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Key points

- This was a multisite pilot study investigating the implementation of a standardised perioperative nutrition pathway for patients undergoing upper gastrointestinal cancer surgery compared to standard care.
- Thirty-five patients were included in the study and were compared with 35 historical controls.
- The percentage of participants receiving preoperative dietetic intervention increased from 55% to 100% ($p < 0.001$). Mean ± SD dietetics contacts increased from 2.2 ± 3.7 to 5.9 ± 3.9 ($p < 0.001$). The recruitment rate was 81%, and adherence to the nutrition pathway was > 70% for all stages of the pathway.
- Larger prospective studies are required to investigate optimal standardised methods of nutrition support in this patient group. This pilot study demonstrated that a larger trial would be feasible to implement.

INTRODUCTION

Upper gastrointestinal (UGI) cancers include oesophageal, pancreatic and gastric tumours, which are responsible for high cancer-related morbidity and mortality wordwide.[1] Malnutrition is common in UGI malignancy, affecting between 40% and 80% of patients.[2–4] Malnutrition is an independent risk factor for increased mortality, surgical complications, length of stay (LOS), and decreased oncological treatment tolerance and quality of life in cancer populations.[5] Practice guidelines recommend early nutrition support for cancer patients undergoing major abdominal surgery,[5,6] which is often the only available curative treatment for UGI cancers. However, best practice guidelines for the optimal timing, process or format for nutritional intervention specific to UGI cancers do not currently exist.[7] As such, there are significant variations in the nutritional practices of dietitians and surgeons for patients with UGI cancer.[8,9] Australian research has found that as few as 5% of patients receive dietetic assessment in the preoperative period, which may be attributed to lack of outpatient dietetic resources and formal management pathways.[9]

Structured and process-driven nutrition care pathways provide support for the nutritional management of oncology patients.[10] Care pathways are complex interventions that support shared decision making and care provision for identified patient groups over a specified period of time, for the purpose of improving risk-adjusted patient outcomes, promoting patient safety and satisfaction, and optimising resource allocation.[11] Several previous studies have identified benefits of nutrition care pathways for nutritional status, treatment tolerance and clinical outcomes in non-surgical oncology populations.[12] However, no existing research has investigated the effect of a perioperative nutrition care pathway in an UGI surgical oncology population. The primary aim of this multisite pilot study was to determine whether implementation of a perioperative nutrition care pathway improves access to dietetics care compared to standard nutrition care. Secondary aims were to evaluate the study's feasibility, fidelity, resource requirements and the effect on clinical outcomes.

METHODS

Study design and setting

This was a prospective pilot study, with historical controls as standard care. The nutrition pathway was implemented across three major metropolitan tertiary centres for UGI surgery in Melbourne, Australia. The lead site was an outer suburban centre performing over 40 UGI cancer resections per annum. The second and third sites were inner city centres, performing approximately 40 and 20 UGI cancer resections per annum, respectively. A specialist inner city oncology centre was also included as a fourth site because preoperative chemotherapy/radiotherapy care is provided here for some patients undergoing surgery at site three. Patients in the intervention group provided written consent to participate in the study. Ethics approval was sought and received from the relevant Human Research Ethics Committee (HREC/18/MH/90) in June 2018, with site governance then secured prior to commencement. The study complies with the reporting of observational studies in epidemiology (STROBE) guidelines.[13]

Development and implementation of the nutrition care pathway

Local quality improvement activities revealed discrepancies between preoperative dietetics service provision and evidence-based guidelines at the participating sites. In particular, no structured preoperative outpatient service was provided. At all sites, the key identified barrier to

dietetics care was lack of available funding and a standardised process to utilise dietetics resources. A multisite partnership was formed to develop and pilot a standardised perioperative nutrition care pathway. Evidence-based practice guidelines specific to UGI cancers are not available; therefore, the nutrition care pathway was developed from a review of existing general surgical and oncology guidelines from the European Society of Clinical Nutrition and Metabolism (ESPEN)[5,6] and Dietitians Associations of Australia/New Zealand[14] (Table 1). Professional consensus was sought where there were no pre-existing recommendations. Agreement on the final content was obtained from expert dietitians ($n = 6$), dietetic managers ($n = 4$) and surgical and oncology stakeholders ($n = 4$–10) at each site. The nutrition care pathway was designed to be led by dietitians, who would identify and self-refer all new patients into the pathway by attending the weekly surgical oncology multidisciplinary meeting where new cases were discussed. The pathway was enabled by commencing a weekly preoperative nutrition outpatient clinic that was colocated within the pre-existing surgical oncology clinic. The pathway included guidelines for the timing, frequency and type of dietetics intervention patients should receive based on nutrition risk stratification, for the following stages of the patient's treatment journey: diagnosis/planning, neoadjuvant therapy (if applicable), presurgery and surgery. Although the pathway provided overarching guidelines, dietitians provided individualised medical nutrition therapy (MNT) according to each patient's clinical situation and preferences, as per usual dietetics practice. This included assessment of energy/protein intake against targets, assessment of anthropometry and weight change, and clinical signs and symptoms. Standard nutrition formulas were utilised for MNT according to each site's usual practice. Because the evidence for preoperative oral immunonutrition remains unclear,[5] this was not utilised. An attempt to include preoperative carbohydrate loading was made; however, this required a change to hospital-wide fasting procedures at two sites and was outside the scope of the study. For the purposes of the present study, the pathway concluded at the end of the patient's surgical admission, with dietitians arranging follow-up post discharge once the patient had completed the study as per standard care procedures. Figure 1 describes the screening and initial assessment/intervention stage of the pathway, with the full nutrition care pathway provided as Supporting information (File S1). The pathway was implemented between September 2018 and August 2019 by surgical oncology dietitians, each with at least 6 years of clinical experience. A facilitated implementation strategy was utilised, which included oversight from an experienced project lead, and a dedicated project officer. Key dietetics, surgical, oncology, nursing and executive stakeholders were engaged throughout the implementation process. This included regular email updates, presentation and discussion at surgical/oncology team meetings and targeted posters. The project team conducted site visits for context analysis with the lead dietitian and manager aiming to identify site-specific processes, facilitators and barriers, as qualitatively described by the lead dietitian and manager. Prior to the pilot period, site study dietitians participated in training to ensure familiarity with the pathway, as well as the study processes. The project lead also made site visits before commencement to support site start up, and again, halfway through recruitment.

Participants

Patients newly diagnosed with UGI cancer between September 2018 and March 2019, who were planned to receive curative intent surgery with or without neoadjuvant therapy were eligible. Patients were included if they were aged ≥ 18 years, within 1 month of their initial presentation at the site's multidisciplinary meeting with a confirmed diagnosis of primary oesophageal, gastric or pancreatic cancer, and were able to consent via English language or an interpreter. Patients were excluded if they were undergoing palliative or non-surgical treatment, or were unable to consent. For the control group, patients who had had surgery for gastric, oesophageal or pancreatic cancer between 2015 and 2017 (before pathway implementation) were identified using lists of medical record coding by surgery type at each site. To minimise bias towards a particular surgery type, controls were selected consecutively from the list of medical records, and selection ceased once the controls reached the same number of participants as the intervention group for each surgery type. The control group received standard dietetics care, which did not involve any formal preoperative dietetics service or protocols, other than *ad hoc* referrals from medical staff.

Outcomes

Data for the nutrition pathway group were prospectively documented using purpose-built data collection forms by the study dietitians after each patient contact. Data for the control group were collected from patients' medical records by the study's project officer who was blinded to the results of the prospective group at the time of data collection.

Access to dietetics care

Dietetics care was assessed using service delivery outcomes and data regarding provision of nutrition support according to the pathway recommendations. Service delivery outcomes included the proportion of patients who received dietetics intervention, dietetics contacts for the entire preoperative period (baseline–surgery) and for each

TABLE 1 Evidence to support recommendations for each stage of a standardised upper gastrointestinal surgical oncology nutrition pathway that was developed and implemented in 2018.

Nutrition care pathway component	Nutrition care pathway stage	Recommendation	Guideline	Strength of evidence
Screening and assessment	**Across all stages**	Screening should be performed for all cancer patients at diagnosis and at repeated intervals throughout each stage of treatment, using validated tools.	DAA/DNZ 2013[a]	B[d]
		Nutritional intake, weight change and BMI should be evaluated at cancer diagnosis and repeated depending on the stability of the clinical situation	ESPEN Cancer 2016[b]	VERY LOW[e]
		Nutrition assessment should be performed for high risk cancer patients using validated tools such as the PG-SGA	DAA/DNZ 2013	B[d]
Intervention	**Across all stages-general nutrition support principles in cancer surgery**	Perioperative nutritional therapy is indicated in cancer patients with malnutrition and those at nutritional risk	ESPEN Surgery 2016[c]	A[f]
		Dietary counselling, treatment of symptoms ± oral supplements in cancer patients undergoing chemotherapy/radiotherapy	DAA/DNZ 2013	A[d]
			ESPEN Cancer 2016	MODERATE[e]
		Dietary counselling ± oral supplements shall be given to all malnourished cancer patients undergoing major abdominal surgery	ESPEN Surgery 2016	GOOD PRACTICE POINT[e]
		If oral intake is inadequate, enteral nutrition should be initiated	DAA/DNZ 2013	C[d]
			ESPEN Cancer 2016	MODERATE[e]
			ESPEN Surgery 2016	GOOD PRACTICE POINT[f]
		If oral or enteral intake is inadequate, or unable to be provided (e.g., nonfunctional gut), parenteral nutrition should be initiated	DAA/DNZ 2013	B[d]
			ESPEN Cancer 2016	MODERATE[e]
			ESPEN Surgery 2016	A[f]
	Diagnosis/neoadjuvant	All patients with UGI cancer receiving radiotherapy should be referred to a dietitian (and/or nutrition support) at the commencement of treatment and their status be reviewed weekly	DAA/DNZ 2013	A[d]
		For patients undergoing radiotherapy for oesophageal cancer who have poor intake, prophylactic enteral feeding tube insertion may be beneficial.	DAA/DNZ 2013	C[d]
			ESPEN Cancer 2016	LOW[e]
	Presurgery	Patients with severe nutritional risk shall receive nutritional therapy prior to major surgery (A) even if operations including those for cancer have to be delayed. A period of 7–14 days may be appropriate (0)	ESPEN Surgery 2016	A/0[f]
		Patients undergoing major UGI (including pancreatic) surgery should be considered for placement of a jejunal feeding tube (nasojejunal or jejunal)	ESPEN Surgery 2016	B[f]
	Inpatient surgical admissions	Early tube feeding (within 24 h) shall be initiated in patients in whom early oral nutrition cannot be started, and in whom oral intake will be inadequate (< 60%) for more than 7 days	ESPEN Surgery 2016	A[f]

TABLE 1 (Continued)

Nutrition care pathway component	Nutrition care pathway stage	Recommendation	Guideline	Strength of evidence
		It is recommended to start tube feeding with a low flow rate and to increase the feeding rate carefully and individually as a result of limited intestinal tolerance. The time to reach the target intake may take 5–7 days	ESPEN Surgery 2016	GPP[f]
Nutrition requirements	**Diagnosis/neoadjuvant therapy/presurgery**	Energy expenditure should range between 25–30 kcal kg^{-1} day^{-1}	DAA/DNZ 2013	C[d]
		Protein requirements should range between 1.2*−1.5 g kg^{-1} day^{-1}	ESPEN Cancer 2016	LOW[e]
	Surgical inpatient admission	Energy expenditure should range between 25–35 kcal kg^{-1} day^{-1} Protein requirements can be up to 1.5 g kg^{-1} day^{-1}	ESPEN Surgery 2016	GOOD PRACTICE POINT[f]
Follow up and monitoring	**Diagnosis/neoadjuvant therapy/presurgery**	Patients should have their weight and food/energy intake monitored regularly to determine whether energy requirements are being met.	DAA/DNZ 2013	C[d]
		Nutrition reviews should occur every 1–2 weeks for moderate risk patients, more frequently in high risk patients	Professional consensus	
	Surgical inpatient admission	Nutrition reviews should occur every 1–2 days depending on the patient's nutritional risk, postsurgical course and progress	Professional consensus	
		Patients should be educated on discharge and receive postoperative monitoring of nutritional status	ESPEN Surgery 2016	GOOD PRACTICE POINTf

[a]DAA/DNZ 2013, Dietitians Association of Australia and Dietitians New Zealand: Updated evidence-based practice guidelines for the nutritional management of patients receiving radiation therapy and/or chemotherapy.[14]

[b]European Society of Clinical Nutrition and Metabolism (ESPEN) Cancer 2016: Guidelines on nutrition in cancer patients.[6]

[c]European Society of Clinical Nutrition and Metabolism (ESPEN) Surgery 2016: Guidelines on clinical nutrition in surgery.[5]

[d]DAA/DNZ 2013 Evidence Strength using National Health and Medical Research Council (NHMRC) evidence grades. A, body of evidence can be trusted to guide practice; B, body of evidence can be trusted to guide practice in most situations; C, body of evidence provides some support for recommendation(s) but care should be taken in its application; D, body of evidence is weak and recommendation(s) must be applied with caution.

[e]ESPEN Cancer 2016 Evidence strength using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) method. High = we are very confident that the true effect lies close to that of the estimate of the effect. Moderate = we are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different. Low = our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of the effect. Very Low = we have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect.

[f]ESPEN Surgery 2016 Evidence strength using the Scottish Intercollegiate Guidelines Network (SIGN). A, At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results; B, A body of evidence including studies rated as ++, directly applicable to the target population; or a body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results: or extrapolated evidence from studies rated as 1++ or 1+, 0 = evidence level 3 or 4; or extrapolated evidence from studies rated as 2++ or 2+. GPP, good practice points. Recommended best practice based on the clinical experience of the guideline development group.

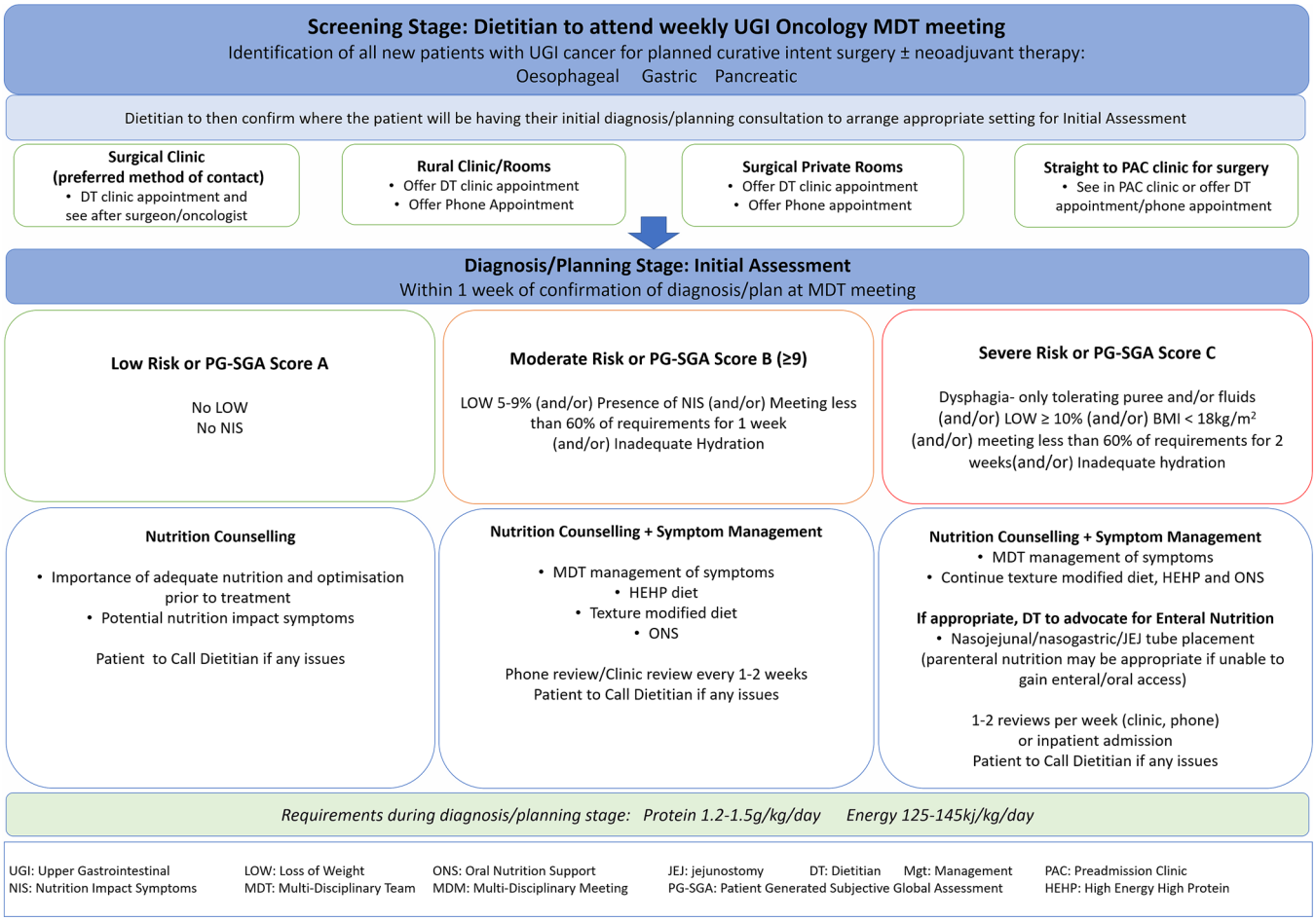

FIGURE 1 Screening and initial assessment stages of the nutrition care pathway. BMI, body mass index

pathway stage (diagnosis, neoadjuvant treatment, presurgery, surgery, as outlined in the pathway). Unsuccessful attempts to contact patients were not included as consultations. Nutrition support outcomes included preoperative and intraoperative feeding tube insertions and the number of days each patient was provided enteral nutrition (EN), oral nutrition support (ONS) and/or parenteral nutrition (PN) within the first 7 days post surgery.

Study feasibility

The recruitment and retention statistics of participants were recorded to assess feasibility of the study, and also to provide data for future larger-scale studies. Because this was a pilot study, no predefined targets for recruitment or feasibility were set.

Fidelity and adherence to nutrition care pathway recommendations

Complex interventions are more susceptible to unwarranted variation, which may compromise the degree to which the intervention is delivered as intended.[15] Detailed reporting of delivery practices is recommended as a means of understanding this practice diversity.[16] The fidelity and adherence to the pathway were evaluated using purpose-built data extraction forms to collect data on adherence to timing on interventions, frequency of follow up and prescribed interventions. Dietitians completed these forms after each consultation, with the reasons for deviation (e.g., being unable to contact a patient) from the pathway documented.

Resource requirements

Resource requirements were estimated by recording the time spent with the dietitian at each consultation. Dietetics time (h) was recorded for the entire preoperative period (baseline–surgery) and separately for each stage of the pathway. Time spent attending the multidisciplinary meeting, screening/coordinating patients' appointments and for follow up were estimated by dietitians weekly to reflect the time taken for complete delivery of care according to the pathway and not just patient contact.

Nutritional outcomes

Weight was measured at baseline and at the time of surgery using calibrated standing scales at each site in the intervention group and was recorded from the medical record in the control group. Nutritional status and hand grip strength (HGS) were collected at baseline and at the time of surgery (within 5 days of surgery) for the intervention group. Nutritional status was assessed by the validated patient generated subjective global assessment (PG-SGA).[17] HGS was measured for the prospective group as a surrogate measure of muscle mass.[18] No PG-SGA or hand grip data were collected for the control cohort as these measures were not conducted as part of routine clinical care and were therefore unavailable.

Surgical and oncology outcomes

Oncology outcomes included preoperative hospital admissions, and preoperative nutrition-related hospital admissions (defined as admissions for malnutrition/weight loss, requirement of enteral nutrition or hydration, or nausea and vomiting). Surgical outcomes included the surgical LOS (days) post surgery, the requirement for inpatient rehabilitation following surgery and the occurrence of surgical complications; classified as 'no/non-serious' (score of < 3) or 'serious' (score of ≥ 3) using the Clavien–Dindo scoring system.[19] Data were extracted from the patients' medical records.

Statistical analysis

The sample size was pragmatic, based on a recruitment period of 6 months for this pilot project and available funding. For intervention patients who withdrew from the study, the participant was still included in the study using the dietetics contacts data already collected; however, surgical outcomes were not able to be measured. Therefore, surgical outcomes were also not measured for an equal number of the consecutively selected controls. Descriptive statistics were utilised to report baseline characteristics of the groups. Data are reported as the mean ± SD or median (interquartile range) as appropriate. Continuous data were analysed using independent samples *t* test accounting for unequal variances for normally distributed data or the Mann–Whitney *U* test for non-normally distributed data. Dichotomous data were analysed using Fisher's exact test. $p < 0.05$ (two-sided) was considered statistically significant. Multivariate analysis was not conducted because of the small sample size. A subgroup analysis for surgical oncology outcomes was undertaken for patients who received neoadjuvant therapy, as these patients have a longer preoperative period and are at a higher risk of nutritional decline. Within-group changes for PG-SGA and HGS from baseline–surgery were assessed for the intervention group using paired sample analysis, although between group comparisons were not undertaken for these outcomes as PG-SGA and hand grip data were not available for the control cohort.

RESULTS

Thirty-five patients were recruited into the study and were compared with 35 historical controls. Twelve participants were withdrawn during or shortly after neoadjuvant therapy as a result of the decision not to proceed with surgical management (Figure 2). Demographic and clinical characteristics were similar across the groups; however, the intervention group had a higher proportion of patients who received neoadjuvant therapy (Table 2).

Access to dietetics care, feasibility, fidelity and adherence to nutrition care pathway recommendations

Overall access to dietetics care

Compared with the control group, there was a significant increase in overall, outpatient and phone dietetics contacts before surgery. However, inpatient contacts remained the same (Table 3).

Diagnosis stage

Timeliness of initial contact also significantly increased, with 77% of patients receiving dietetics contact within 1 week of diagnosis as per the pathway (Table 3).

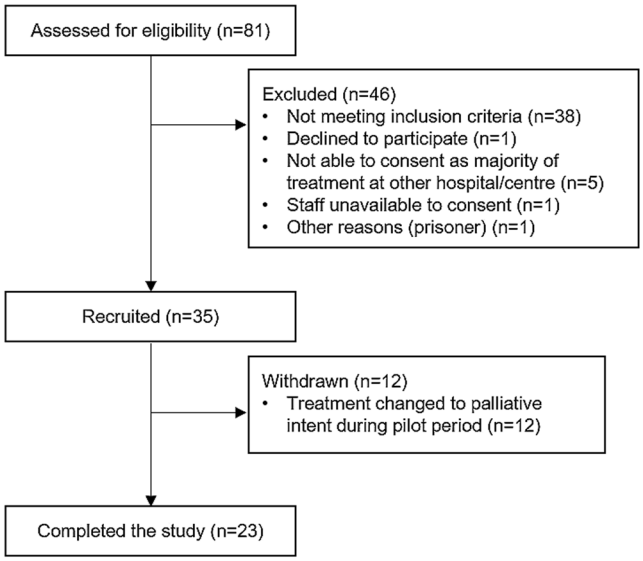

FIGURE 2 Flow diagram of participants

TABLE 2 Demographic and baseline characteristics of intervention and control participants

	Control ($n = 35$)	Intervention ($n = 35$)	p value
Age (years), mean ± SD	65 ± 11	66 ± 12	0.67
Sex, *n*(%)			0.14
Female	17 (49)	10 (29)	
Male	18 (51)	25 (71)	
Residence, *n*(%)			
Metropolitan	26 (74)	29 (83)	0.57
Rural/regional	9 (26)	6 (17)	
Tumour location, *n*(%)			0.45
Gastric	12 (34)	7 (20)	
Oesophageal/oesophagogastric	11 (31)	16 (46)	
Pancreatic/ampullary	12 (34)	12 (34)	
T stage, *n* (%)			0.24
T0	1 (3)	1 (3)	
T1	6 (17)	9 (26)	
T2	10 (29)	5 (14)	
T3	11 (31)	7 (20)	
T4	4 (11)	3 (9)	
Tx/unable to assess	3 (9)	10 (28)	
Neoadjuvant therapy, *n*(%)	11 (31)	24 (69)	0.004
Surgery type, *n*(%)[a]			0.66
Oesophagectomy	11 (48)	11 (48)	
Subtotal gastrectomy	3 (13)	3 (13)	
Total gastrectomy	3 (13)	3 (13)	
Total pancreatectomy	0 (0)	1 (4)	
Whipple's or partial pancreatectomy	6 (26)	5 (22)	
Previous dietetics input, *n*(%)[b]	9 (26)	11 (33)	0.60
Previous dietetics input setting, *n*(%)[c]			1.00
Inpatient	9 (100)	8 (89)	
Outpatient	0 (0)	1 (11)	
BMI at baseline (kg m^{-2}), mean ± SD	23.9 ± 11.5	27.8 ± 6.8	0.10
PG-SGA score at baseline (intervention group only)[d]			
PG-SGA A (well nourished)		9 (26)	
PG-SGA B (mild-moderate malnutrition)		18 (53)	
PG-SGA C (severe malnutrition)		7 (21)	

Abbreviations: BMI, body mass index; PG-SGA, Patient Generated Subjective Global Assessment.

[a]Presented as a proportion of those who were included in analysis of surgical outcomes ($n = 23$ in each group).

[b]Previous dietetics input was defined as any prior dietetics consultation or intervention related to this cancer diagnosis.

[c]Presented as a proportion of those who responded 'yes' to previous dietetics input.

[d]Presented as a proportion of ($n = 34$) as one patient was not able to complete the initial PG-SGA.

TABLE 3 Differences in access to dietetics care between intervention and control participants

	Control	Intervention	Mean difference with 95% confidence interval[a]	*p* value
Overall access to dietetics care	***N* = 35**[a]	***N* = 35**[a]		
Seen by dietitian before surgery, *n* (%)	19 (55)	35 (100)	NA	**< 0.001**
Total dietetics contacts, mean ± SD[b]	2.2 ± 3.7	5.9 ± 3.9	3.7 (1.9–5.6)	**< 0.001**
Outpatient contacts, mean ± SD[b]	1.0 ± 2.7	3.7 ± 2.7	2.6 (1.3–3.9)	**< 0.001**
Phone contacts, mean ± SD[b]	0.1 ± 0.3	1.0 ± 1.3	0.9 (0.5–1.4)	**< 0.001**
Inpatient contacts, mean ± SD[b]	1.1 ± 1.9	1.4 ± 3.0	0.4 (−0.9 to 1.6)	0.56
Access to dietetics care per stage of the pathway				
Diagnosis stage				
Received dietetics contact within 1 week of diagnosis, *n* (%)	11 (31)	27 (77)	NA	**< 0.001**
Total dietetics contacts diagnosis stage, mean ± SD	1.0 ± 2.3	1.9 ± 1.8	0.9 (1.0–2.7)	0.32
Outpatient	0.3 ± 0.7	0.9 ± 0.7	0.5 (−0.02 to 1.1)	0.06
Phone	0.2 ± 0.4	0.6 ± 0.9	0.3 (−0.1 to 0.8)	0.15
Inpatient	0.4 ± 1.3	0.4 ± 1.5	0.0 (−1.1 to 1.1)	0.97
Neoadjuvant stage				
Total dietetics contacts neoadjuvant stage, mean ± SD	4.6 ± 3.9	5.1 ± 4.2	0.5 (−3.3 to 4.3)	0.77
Outpatient	4.0 ± 3.6	3.4 ± 1.9	−0.6 (−3.9 to 2.7)	0.68
Phone	0.0 ± 0.0	0.3 ± 0.7	0.3 (−0.4 to 0.6)	0.08
Inpatient	0.6 ± 1.0	1.4 ± 3.3	0.8 (−0.9–2.4)	0.33
Presurgery stage				
Total dietetics contacts presurgery stage, mean ± SD	0.9 ± 1.4	1.5 ± 1.0	0.7 (−0.5–1.9)	0.25
Outpatient	0.4 ± 0.5	1.0 ± 0.7	0.6 (0.1–1.1)	**0.03**
Phone	0.0 ± 0	0.5 ± 0.8	0.5 (0.2–0.9)	**0.01**
Inpatient	0.5 ± 1.4	0.1 ± 0.2	−0.5 (−1.6 to 0.7)	0.40
Surgical admission				
Total dietetics contacts surgery stage, mean ± SD[b,c]	10.7 ± 12.3	13.2 ± 14.1	2.5 (−5.3 to 10.4)	0.52
Feeding tube insertions				
Feeding tube insertions during neoadjuvant therapy, *n* (%)[c]	0 ± 0	5 ± 22	NA	0.05
Intra-operative feeding tube insertions, *n* (%)[c]	11 ± 48	16 ± 70	NA	0.23

Abbreviations: CI, confidence interval; NA, not applicable.

[a]Measured from baseline (diagnosis) to surgery.

[b]Patients included until time of withdrawal as per statistical analysis section.

[c]Patients who were not withdrawn from the study ($n = 23$ for each group).

Although not statistically significant, there was an increase in total ($p = 0.32$), outpatient ($p = 0.06$) and phone ($p = 0.15$) contacts. Again, inpatient contacts remained the same ($p = 0.97$).

Neoadjuvant stage

For patients having neoadjuvant therapy, total and phone contacts increased, although the increases were also not statistically significant ($p = 0.77$ and 0.08, respectively) (Table 3). Outpatient contacts decreased slightly ($p = 0.68$), whereas inpatient contacts increased ($p = 0.33$). However, these results were also not statistically significant.

Presurgery stage

The overall contacts in this stage also increased, but not significantly ($p = 0.25$). However, outpatient and phone

contacts both increased significantly ($p = 0.03$ and 0.01, respectively). Inpatient contacts decreased, but this was not significant ($p = 0.40$)

Inpatient surgical stage

Total dietetics contacts for the surgical admission did not change (Table 3). Early commencement of oral or enteral nutrition was adhered to in 74% ($n = 17$) of patients in the intervention group and 78% of patients in the control group ($n = 18$) (see Supporting information, File S2). Dietetics input and interventions, including overall dietetics contacts and provision of ONS, EN and PN, also did not change (see Supporting information, File S2).

Enteral and parenteral nutrition access

Clinically meaningful increases were demonstrated in rates of preoperative feeding tube insertions (22%, $n = 5$ vs. 0%, $p = 0.05$) and intraoperatively (70%, $n = 16$ vs. 48%, $n = 11$, $p = 0.23$), although not statistically significant (Table 3). All five preoperative feeding tubes were inserted in neoadjuvant therapy and three (60%) of the patients who received these feeding tubes were malnourished. There were no requirements for preoperative parenteral nutrition.

Study feasibility

The recruitment rate was 81% (Figure 2). However, the withdrawal rate was high at 34% ($n = 12$), which was the result of a change in treatment, from curative intent to palliative. No participants withdrew because if study-related factors and there were no reported adverse events associated with the study.

Fidelity and adherence to pathway recommendations

Screening within 1 week of diagnosis in the multidisciplinary meeting occurred in 91% of patients. The few delays that occurred were attributed to 'coordination with existing medical appointments' and 'patient-related factors' (cancelling, being overwhelmed, being uncontactable). The pathway follow-up schedule was followed 74% of the time, and dietitians were able to prescribe the interventions as per the pathway on 84% of occasions. Reasons for deviation from the pathway included 'difficulties initiating a new model of care' (reported only at the beginning of the study), 'coordination with existing medical appointments', 'patient related factors' (cancelling, being overwhelmed, being uncontactable), or 'clinician's judgement'.

Resource requirements

The mean ± SD estimated dietetic time spent on direct patient contact during the entire preoperative period was 3.7 ± 2.8 h per patient (mean ± SD contacts: 5.9 ± 3.9). Per phase of the pathway, dietetic resources required were 1.3 ± 1.2 h per patient in the diagnosis phase, 3.1 ± 3.0 h in the neoadjuvant phase and 0.9 ± 0.9 h in the presurgery stage. Coordination of pathway appointments, discussion and follow up of management with the MDT was estimated to be 0.5 h per patient per week. Dietitian attendance at the weekly multidisciplinary meeting ranged between 1.0 and 1.5 h per week.

Nutritional outcomes

There were no differences between the groups for preoperative weight change. Weight change for the intervention group ($n = 22$) was −1.3% (4.2%) and, in the control group ($n = 18$), was −0.7% (3.5%) (mean difference 0.6%, 95% confidence interval = −1.9 to 3.1, $p = 0.18$). There was a clinically but not statistically significant reduction in malnutrition in the intervention group between baseline (65%) and surgery (48%) ($p = 0.29$). In the seven participants who were able to complete the HGS test at surgery, muscle strength decreased between baseline and surgery (mean difference −5.0 ± 4.1, 95% confidence interval = −8.76 to −1.3, $p = 0.02$).

Surgical and oncology outcomes

There were no clinically or statistically important between group differences in preoperative hospital admissions, surgical LOS and incidence of surgical complications (Table 4). In the subgroup analysis of neoadjuvant therapy patients, there were nonstatistically significant reductions in nutrition-related hospital admissions (29% vs. 44%, $p = 0.66$), incidence of severe surgical complications and requirement for inpatient rehabilitation (Table 4).

DISCUSSION

The aims of the nutrition care pathway were to enable increased, consistent and proactive outpatient-based care in the preoperative setting, which was previously lacking despite recommendations for optimisation of patients before surgery.[6] In accordance with these aims, implementation resulted in significantly improved preoperative access and timeliness of dietetics care in the outpatient setting. Although the most time spent was for patients undergoing neoadjuvant therapy, this stage of the treatment pathway lasts for a significant period

TABLE 4 Surgical oncology outcomes of intervention and control participants

	Control	Intervention	*p* value
Overall cohort	***n* = 23**	***n* = 23**	
Preoperative hospital admissions, *n* (%)	11 (48)	14 (61)	0.62
Nutrition-related hospital admissions, *n* (%)	4 (17)	4 (17)	1.00
LOS, median (IQR)	14.0 (9–20)	15 (8.8–24.3)	0.90
Severe complications, *n* (%)	7 (30)	7 (30)	1.00
Requiring inpatient rehabilitation, *n* (%)	4 (17)	3 (13)	1.00
Neoadjuvant therapy	***n* = 9**	***n* = 14**	
Preoperative hospital admissions *n* (%)	6 (67)	10 (71)	1.00
Nutrition-related hospital admissions, *n* (%)	4 (44)	4 (29)	0.66
LOS (days), median (IQR)	15 (12–37)	14 (9–23)	0.42
Severe complications, *n* (%)	4 (44)	4 (29)	0.66
Requiring inpatient rehabilitation, *n* (%)	3 (33)	1 (8)	0.26

Abbreviations: IQR, interquartile range; LOS length of stay.

(a minimum of 5 weeks for oesophageal cancer, and longer for gastric and pancreatic cancer). Therefore, the amount of time spent by dietitians during this period was higher than the diagnosis and presurgery stages. Increased rates of feeding tube insertions in neoadjuvant therapy were also demonstrated, which could be a result of the increased and earlier identification of high-risk patients, and discussion of nutrition support with the MDT as outlined in the pathway recommendations. Other studies in haematology patients have demonstrated improved utilisation of enteral feeding with the implementation of a nutrition care pathway.[20,21]

Recent publications for translating nutrition guidelines into clinical practice have recommended that nutrition therapy is delivered as a 'parallel' pathway to the oncological treatment pathway and should begin at diagnosis and continue across the treatment continuum.[10] This is the first study to describe the development and implementation of a nutrition pathway aligned with the entire preoperative UGI oncological treatment pathway. Although there are no guidelines specific to UGI cancer, evidence from existing surgical and oncology guidelines was utilised to develop a pathway of best fit to UGI cancer surgery, as per recent recommendations.[10] The multisite approach to this pilot study had significant advantages for the development of the pathway. The group of nutrition experts, each with significant experience in the management of cancer patients, were able to apply existing guidelines comprehensively and practically in the context of UGI cancer care. Feedback was also sought from surgical and oncology stakeholders across all participating organisations to ensure the pathway was relevant and translatable into clinical practice. The use of a facilitated implementation strategy with guidance from clinicians who had experience in implementing care pathways resulted in a high uptake of the pathway across all sites and a high fidelity and adherence to recommendations. These findings support previous research in cancer cohorts demonstrating that dietitian led, facilitated implementation strategies that also involve engagement with the wider MDT can improve adherence to evidence-based nutrition guidelines in clinical practice.[20–22]

Other studies investigating the use of care pathways in nonsurgical oncology patients have demonstrated improved clinical outcomes including improved LOS and nutritional status.[12] Odelli *et al.*[23] implemented a dietitian-led nutrition care pathway for oesophageal cancer patients undergoing definitive chemoradiation, which resulted in improvements in weight, treatment tolerance and hospital admissions. Their study did not demonstrate any substantial improvements in preoperative weight change, LOS or surgical complications; however, the sample size was small and was underpowered for these outcomes. Furthermore, the overall weight loss was low in both groups, contrary to other studies that have shown higher rates of preoperative weight loss.[24,25] Fifty-five percent of the control group received preoperative dietetics intervention, which could have also influenced the results. However, the mean number of dietetics contacts increased significantly from 2.2 to 5.9. Recent data demonstrates that patients undergoing curative UGI surgery who received ≥ 3 preoperative dietetics appointments had reduced preoperative weight loss and surgical complications compared to those who received zero to two appointments.[26] Therefore, in a larger sample size, the nutrition care pathway may have demonstrated a more significant impact on clinical outcome measures.

Pilot studies with small sample sizes can be used to identify statistically and clinically significant data and, although the results should be judged with caution, they provide scope for consideration of future trials.[27] Because patients who undergo neoadjuvant therapy are at higher risk of nutritional decline and can receive significantly different nutritional management than those who only receive surgery,[5,7] a subgroup analysis was undertaken for this group. Although not statistically significant, reductions were demonstrated for nutrition-related hospital admissions and surgical complications. A larger sample size may have resulted in statistically significant differences. These improvements could be a result of the institution of the nutrition pathway and proactive nutrition care before surgery, as well as the increased initiation of enteral feeding. However, many factors can contribute to these outcomes and a larger sample size with adjustment for confounders is required to confirm these promising initial findings. Early and intensive dietetics intervention has also been shown to

improve weight and surgical complications in oesophageal cancer patients undergoing neoadjuvant therapy ($n = 35$),[24] as well as quality of life in a pilot randomised controlled trial ($n = 21$) of oesophageal and gastric cancer patients undergoing chemotherapy.[25] A dietitian-led clinic for head and neck cancers undergoing (chemo) radiotherapy also demonstrated a reduction in nutrition-related hospital admissions.[28]

The results of the present study enable description of the dietetics resources required to implement the preoperative components of the nutrition care pathway. This was a funded study enabling facilitation of a dietitian-led nutrition care pathway and outpatient service. This resourcing is often typically lacking across health services.[9] However, previous research has described reductions in hospital costs through implementation of evidence-based nutrition care[22] and future studies in UGI cancer cohorts should include cost effectiveness analysis. Other avenues for screening and monitoring of patients' progress that require fewer dietetics resources, such as the use of nutrition assistants, could also be considered. High fidelity and adherence to nutrition pathway recommendations were demonstrated, indicating that implementation was successful overall. However, nutrition pathways are complex interventions and many factors can influence the success or failure of implementation in clinical practice.[29] Although feasibility of recruitment of participants within the study context was described, description and analysis of the implementation process using implementation science can assist in interpretation of the outcomes of the study, and in translating this research into future practice.[27,30] A complex analysis of implementation using the Consolidated Framework for Implementation Research (CFIR) has also been undertaken,[31] which has been reported in an additional manuscript.[32]

Limitations

The main limitation of the present study is the sample size; however, a sample size of 10–30 participants has been suggested as being effective and practical for pilot studies.[27] The aim of this pilot study was to test the intervention and feasibility of recruitment; all of which are of significant importance for clinical studies.[27] The results can be utilised to determine sample size calculations and provide valuable data regarding the feasibility and implementation considerations needed to conduct larger scale trials in the clinical setting.[27,29] The high number of patients who withdrew from the study may have biased the results because these patients still received dietetics care until the point of withdrawal. The use of historical controls was a limitation because funding did not enable a prospective two-armed study, and thus the control group may not be comparable in that it did not include patients who moved to palliative treatment. This could also explain why inpatient contacts increased for the intervention group during the neoadjuvant stage. A further limitation of historical data was that there was insufficient retrospective data to enable comparison of nutritional status and muscle strength between the groups. Dietary intake of patients was unable to be captured via intake validated tools (e.g., a 3-day food diary); however, the study's dietitians assessed dietary adequacy during each consultation via diet history and provided nutritional management according to the pathway.

CONCLUSIONS

This pilot study has described the development and implementation of a perioperative nutrition care pathway in UGI cancer across multiple hospitals. Implementation resulted in improved access to dietetics care according to best available evidence-based recommendations across the early continuum of oncology care. Recruitment feasibility and high fidelity to the intervention were demonstrated. Future prospectively conducted research studies with larger sample sizes are required to determine the best standardised methods of perioperative nutrition support in UGI cancer surgery and the effect on clinical outcomes.

AUTHOR CONTRIBUTIONS

Irene Deftereos, Sally Butzkueven, Kate Fetterplace, Kate Fox, Aurora Ottaway, Kathryn Pierce, Belinda Steer, Jessie Varghese, Vanessa Carter and Justin Yeung contributed to conception/design of the research. Irene Deftereos, Sally Butzkueven, Kate Fox, Aurora Ottaway and Jessie Varghese contributed to acquisition of the data. Irene Deftereos, Nicole Kiss, Justin Yeung, Sally Butzkueven, Danielle Hitch and Janan Arslan contributed to analysis and interpretation of the data. Irene Deftereos drafted the manuscript. All authors critically revised the manuscript; and agree to be fully accountable for ensuring the integrity and accuracy of the work. All authors read and approved the final version of the manuscript submitted for publication.

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CONFLICTS OF INTEREST

ID has received grants from Nestle Health Science (not related to this study). KF has received conference, travel grants and/or honoraria from Baxter, Fresenius Kabi, Nutricia, Abbott and Nestle Health Science (not related to this study). The other authors declare that they have no conflicts of interest.

ETHICS STATEMENT

Ethics approval was sought and received from the relevant Human Research Ethics Committee (HREC/18/MH/90) in June 2018, with site governance then secured prior to commencement.

TRANSPARENCY DECLARATION

The authors affirm that this manuscript is an honest,-accurate and transparent account of the study beingr-eported. The authors affirm that no important aspectsof the study have been omitted and that any discrepancies from the study as planned have been explained.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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ORIGINAL ARTICLE

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Improving patient and carer access to information and support through head and neck cancer treatment and survivorship using experience-based co-design

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Abstract

Background: Previous studies have highlighted the unmet nutritional and supportive care needs of patients with head and neck cancer (HNC) and their carers from diagnosis and throughout the treatment and survivorship period. The aim of this study was to bring patients, carers and healthcare professionals together to co-design a framework to improve access to nutrition information and support for patients and carers with HNC from diagnosis and throughout the treatment and survivorship period.

Methods: Using experience-based co-design (EBCD), semistructured individual interviews were conducted with patients, carers and healthcare professionals to understand their experiences in accessing information and support outside of the hospital environment. Feedback events and co-design workshops were held to prioritise areas for service improvement.

Results: Participants (10 patients, 7 carers and 15 healthcare professionals) highlighted the importance of having consistent information and support recommendations from the multidisciplinary team. The two key areas for improvement identified through group and workshop events were linking reputable HNC resources to a HNC portal on the hospital website and the development of a series of short podcasts and video blogs with fact sheets attached presented by members of the multidisciplinary team, patients and carers at four time points spanning pretreatment and throughout the survivorship period.

Conclusions: Using EBCD has enabled the co-design of a framework for resource development with patients, carers and healthcare professionals to improve access to information and resources to support nutrition intake and supportive care needs for patients with HNC with their carers. Development and implementation of resources and evaluation of outcomes is ongoing.

KEYWORDS

access to information, experience-based co-design, head and neck neoplasm, nutrition support, qualitative research

Key point

Using experience-based co-design has enabled the co-design of a framework for resource development to improve access to nutrition care information and support for patients with head and neck cancer and their carers.

INTRODUCTION

Head and neck cancer (HNC) is defined as tumours within mucosal surfaces of the oral cavity, pharynx, larynx, paranasal sinuses and salivary glands.[1] HNC is one of the sixth most commonly diagnosed cancers globally, with 66% of cases being diagnosed at advanced stages of the disease.[2] A history of alcohol and tobacco use is the main risk factor for HNC; however, infection with human papillomavirus has been identified as the main risk factor for tumours within the oropharynx, especially in younger adults.[3]

Treatment for HNC is complex, with the acute and chronic side effects of treatment, including dysphagia, xerostomia, dysgeusia, poor dentition and trismus, impacting greatly on the patient's ability to eat and drink.[4] Eating problems affect the everyday life of patients with HNC in many ways and can challenge relationships, with friends and family assisting them with their nutrition intake and other supportive care needs.[5] Studies have found that many patients and their carers have unmet needs for support which can impact negatively on their ability to cope and contribute to isolation and social withdrawal.[6–8] Due to the physical and psychological impact of HNC on the patient and carer, coordinated care provided by a multidisciplinary team, including surgeons, oncologists, dentists and nursing and allied health professionals, is essential in the provision of person-centred care.[9] In a study exploring patient and carer experiences of nutrition care at different time points extending from diagnosis to 1-year posttreatment completion, we found tensions in the care relationships between patients, carers and healthcare professionals in the provision of nutrition care.[10] This study highlighted the challenges carers face in trying to access information and support independently of the patient.[10] Contributing to this tension are the changing nutritional needs and focus of patients throughout their treatment and recovery journey.[10] Currently, there is no accepted standard follow-up care for HNC survivors.[5] Exploring a dyadic model of nutrition care, we found there is a need for healthcare professionals to recognise patients and their carers as a team to ensure their physical and psychological needs are met throughout the treatment and survivorship period.[6] Experience-based co-design (EBCD) is a form of participatory action research that draws on the experiences of patients, carers and healthcare professionals to improve the quality of healthcare provided.[11] After first being piloted to improve service delivery to patients with HNC, the use of EBCD has gained international momentum across an increasing number of healthcare services.[12] With the aim of ensuring better outcomes for all, EBCD provides patients, carers and healthcare professionals with an equal voice to participate as active partners in healthcare improvement.

The aim of this study was to bring patients, carers and healthcare professionals together to co-design a framework for collaborative resource development to improve access to nutrition information and support for patients and carers of patients with HNC from diagnosis and throughout the treatment and survivorship period. As EBCD is rapidly emerging as a new form of participatory action research, this paper provides a description of the processes used by healthcare professionals, patients and carers to prioritise areas for service improvement.

METHODS

This study was designed in line with the EBCD toolkit prepared by the Australian Healthcare and Hospitals Association and Consumers Forum of Australia,[13] which uses resources developed from the Point of Care Foundation in the United Kingdom and Healthcare co-design in New Zealand.[14,15] The steps of this approach are provided here (Figure 1) and include setting up the study with key stakeholders; gathering and understanding the experiences of patients, carers and staff; and working collaboratively to identify and prioritise a framework for resource development.

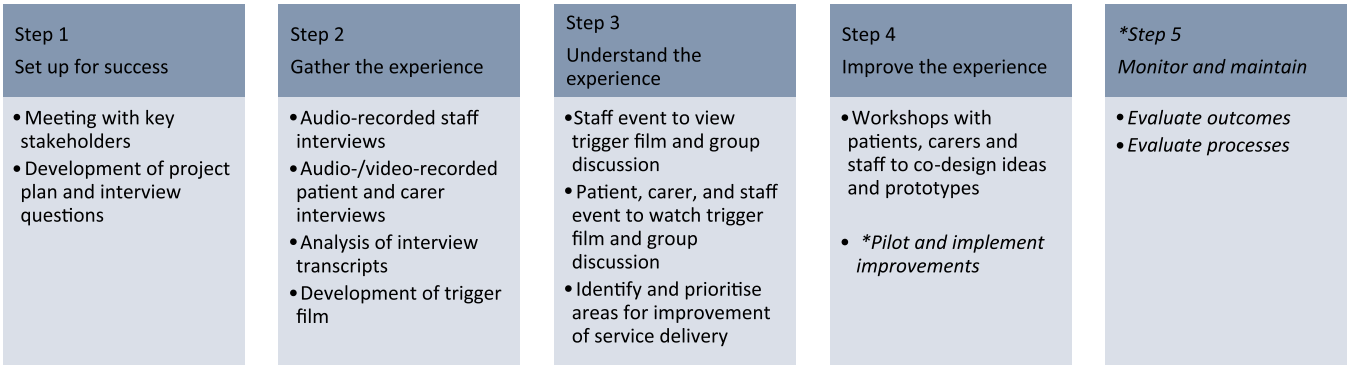

FIGURE 1 Experience-based co-design (EBCD) method adapted from the EBCD toolkit[13]. *Steps not completed in this study.

No funding was provided for this study. All patients and carers volunteered their time to participate, with staff participating in work time. The principal investigator (J. H.) works as a dietitian in HNC, has previously provided clinical care for patient and carer participants and has worked alongside staff participants in this study.

Step 1: set up for success

The key stakeholders involved in this study included a medical oncology consultant, radiation oncology consultant, speech pathologist, social worker, psychologist, dietitian, cancer care coordinator and consumer representative (treated for HNC 17 years prior, active patient advocate at the national level). Key stakeholders were involved in the development of the project plan, including interview questions and workshop design.

Step 2: gather the experience

Staff experiences

Staff members were recruited from a tertiary/quaternary hospital in Brisbane, Australia. Staff members were approached to participate if they had at least 12 months' experience working with patients having radiation treatment at the Royal Brisbane and Women's Hospital (RBWH). Purposive sampling was used to select staff from a range of disciplines within the HNC multidisciplinary team. A semistructured interview guide was developed based on findings from previous studies carried out by the principal investigator (J. H.) exploring patient and carer experiences of nutrition care[10] and used to explore staff experiences working with patients and carers seeking information and support with a focus on nutrition. Interviews were conducted face to face at a location suitable to each staff member over a 2-month period between April and May 2021 by the principal investigator (J. H.). Interviews were audio-recorded and transcribed verbatim.

Patient and carer experiences

Patients and carers were recruited from the radiation oncology department at a tertiary/quaternary hospital in Brisbane, Australia. Patients and carers were approached to participate if they could speak English and aged above 18 years and the patient had completed radiation treatment 3–12 months earlier at the RBWH. Convenience sampling was used to recruit patient and carer participants. A semistructured interview guide was used to explore patient and carer experiences in seeking information and support throughout the cancer treatment trajectory and recovery period with a focus on nutrition. Interviews were conducted face to face, via telehealth or telephone as per participant preference. All interviews were audio-recorded and transcribed verbatim by the principal investigator (J. H.). Face-to-face and telehealth interviews were video recorded.

Data analysis

Inductive analysis of staff, patient and carer interview transcripts was performed using reflexive thematic analysis by the principal investigator (J. H.).[16] To enhance rigour, meetings were held with the associate investigator (A. Y.) to discuss and reflect on the interpretation of interview text to support a reflexive approach.

Trigger film production

Video footage and audio transcripts from patient and carer interviews were used to produce a 20-min film, also known as a 'trigger film', to spark discussions in the following steps of the EBCD process. Videoscribe, an animation software, was used to produce the film as it provided a platform to use drawings to capture the experiences of patients and carers who were not video recorded.[17] Throughout production, the film was reviewed by the principal investigator (J. H.) and associate investigators (A. Y., T. B., J. B. and M. B.) to further solidify themes, also referred to as 'emotional touch points' in EBCD methodology. All participants were sent a copy of the video to review themes and their representation in the film and to obtain consent to distribute to other patients, carers and staff.

Step 3: understand the experience

Staff event

A staff event was held in October 2021 for members of the multidisciplinary cancer care team to view the trigger film prior to watching it with patients and carers present. As previous studies have demonstrated the powerful impact trigger films can have on staff, this was held as a separate event to enable open discussion of feelings evoked prior to watching alongside patients and carers in the patient, carer and staff event.[12,18] The video was played using Microsoft Teams, and staff members were asked to provide feedback on the film via a chat function within the software and to ask questions at the end of the film. Prior to watching the video, staff members were asked to consider areas to prioritise to improve access to information and support based on patient and carer experiences shown in the film.

Patient, carer and staff event

Patients, carers and staff members were invited to a screening in November 2021 of the same trigger film shown in the separate staff event followed by a presentation of staff experiences delivered by the principal investigator (J. H.). Invitations to this event were sent to staff, patient and carer participants who participated in step 2 of the study, staff members who participated in the separate staff event in step 3 of the study and patients and carers of patients who recently completed radiation treatment. During this event, participants were asked by the workshop facilitator (J. H.) to reflect on the emotional impact of the experiences shared by patients, carers and staff by enabling discussion of points raised. At the end of this event, participants were asked to prioritise areas they felt were the most important to improve access to information and support through group discussion. The workshop facilitator ensured each participant was given equal opportunity to contribute to ensure that joint priorities were established for service improvement.

Step 4: improve the experience

Co-design workshops

Invitations were sent to patients, carers and staff who had previously been invited to participate in step 3 of the study to participate in co-design workshops to design and plan for implementation areas jointly prioritised for service improvement. Two separate workshops were held in November 2021.

RESULTS

Participation

Each step of the co-design method involved patients, carers and healthcare professionals. Table 1 provides an outline of participant numbers included in each of the four steps of EBCD used in this study.

Staff interview themes

Nine staff members, namely a radiation oncologist, medical oncologist, speech pathologist, psychologist, social worker, cancer care coordinator, dietitian, radiation oncology nurse and medical oncology nurse, participated in the interviews. Staff interview themes are presented in Table 2. Overall, staff emphasised the importance of being able to direct patients and carers to reputable sources of information and support to alleviate the distress and anxiety that misinformation

TABLE 1 Participant numbers throughout each step of the study

Steps included in study	Step 1: set up for success	Step 2: gather the experience		Step 3: understand the experience		Step 4: improve the experience	
Activity	Key stakeholder engagement	Staff interviews	Patient and carer interviews	Staff event	Patient, carer and staff group event	Workshop 1	Workshop 2
Number invited	8	9	19 patients	>100	15 patients	15 patients	15 patients
			23 carers		15 carers	15 carers	15 carers
					24 staff members	24 staff	24 staff members
Invitation method	Individual email	Individual email	Telephone	Group email to Cancer Care Services	Individual email	Individual email	Individual email
Number of participants	8	9	10 patients	15 staff members	2 patients	3 patients	3 patients
			7 carers		0 carers	0 carers	1 carer
					2 staff members	3 staff members	0 staff member

can create. Across the multidisciplinary team there was inconsistency in awareness of existing specific HNC resources available to support patients and carers; however, all participants acknowledged the importance of having consistent information and support recommendations provided by each member of the multidisciplinary team. This included being able to refer to online resources specifically to support patients and carers with their nutrition care needs. Staff participants recognised that patients and carers had different information and support needs throughout the treatment trajectory and that many carers feel they are unable to ask for help, feeling the focus must remain on the patient.

Patient and carer interview themes

Ten patients and seven carers participated in interviews. Seven patients and four carers consented to their interviews being video recorded, with three patients and three carers expressing their preference to participate in an audio-recorded interview. One patient and one carer withdrew from the study after watching the trigger film. Patient and carer interview themes are presented in Table 3. Patients and carers spoke about their trust in information provided to them from healthcare professionals. All participants used the internet at different times throughout their treatment and recovery to seek information and support; however, some participants expressed how this caused them greater distress than benefit. Being able to access reputable sources of information was preferred, and some participants expressed their preference to being able to access information through the hospital website where they were having their treatment and felt they could trust that information provided would be from the healthcare professionals involved in their treatment. More specific information on HNC symptom management, exercise and nutrition through the hospital website was desired. Some

TABLE 2 Staff interview themes

Staff interview themes	
Concern about online information	'I've had people say to me I saw some stuff [online] and then I stopped looking because it was basically too anxiety provoking. And I imagine that's happening more than what people report, and they're just kind of keeping it to themselves' (psychologist)
	'I try and keep open communication about information online and try to be non-judgemental so people feel they can tell me what they have learned. Knowing I guess the amount of misinformation out there' (dietitian)
	'Yeah, there's big forums and like I say to patients and their carers, it's like childbirth, you're only going to hear the bad stories. You don't hear the good ones, so be careful what you read online because sometimes it can really throw you off and skew your perception about what is actually going to happen' (nurse, radiation oncology)
Empowering patients and carers with information	'I think health outcomes are not just reliant on a diagnosis, it's relying on so many other factors and one of them is the education and information people have' (social worker)
Patients and carers have different information and support needs	'I think the patients' moods are affected by not eating and drinking properly for so long, so I think they have a lot of mood symptoms which impact on the relationship with the partner. So, there is a difference between what the patient and carer need in that middle part of treatment' (medical oncologist)
Need online resources that meet patient and carer needs	'I don't know that there are enough online resources for our patients. It would be good if we could point them in the right direction' (nurse, medical oncology)
	'I guess a portal for patients and carers and family members. Just a very basic easy to use system. Like this is how much nutrition you need, and this is why you need it' (nurse, medical oncology)
Consistency in information provided by the multidisciplinary team	'I think it would be good if we could be more standardised with the information, we suggest our patients look up after treatment. At least that way we are giving them a list of reputable sources and some patients may choose to look more into it than others' (radiation oncologist)
	'I've had feedback from the nursing unit manager in the day therapy unit just wanting to know how else they can help us support the patients because they find patients come in and they want to know they are telling the patient the same information we are telling the patient' (cancer care coordinator)
Carers need support too	'I get the feeling that carers feel like the focus is on the patient. I can't ask for …, I shouldn't be asking for …, I shouldn't be asking for something for me' (speech pathologist)

TABLE 3 Patient and carer interview themes

Patient and carer interview themes	
Trust in healthcare professionals and information provided	'I put a lot of trust in the healthcare professionals that were dealing with her at the time' (Carer 1)
Getting lost in the internet	'I was looking at a news feed that comes automatically to my phone and one day I clicked on this particular news feed which said someone is dying with cancer, and this is just before I started my treatment. And then the way this works is once you have clicked on the cancer keyword, they send you all the news related with cancer, so I was continuously getting stories for three months about all the people dying from cancer' (Patient 1.) 'One of the guys told me to stay off the internet because there is so much information that can be right or wrong and it can mess with your head' (Patient 2)
Preference for reputable sites for information	'I was conscious that there was so much information out there that when I did go looking for what I though might be some advice or at least assistance, I deliberately narrowed myself to what to knew to be reputable sites' (Patient 3) 'I went to the Royal Brisbane and Women's Hospital website to look at the videos and the testimonials there and that was good to know that it was actually coming from health experts and people we are going to' (Patient 1)
Wanting specific information	'It would be valuable if there was just one space where you go and look at a series of problems that are likely to occur and information about treating those problems, ranging from xerostomia to your teeth, to taste, to exercise and for nutrition' (Patient 3) 'More meal recommendations or preparation just to really ease the burden of having to think for themselves' (Carer 1)
One-on-one peer support	'An important thing for anybody would be that they have someone to talk to about it that has had it and knows what they are going through' (Patient 4) 'To hear someone else's story can help you, because sometimes it might just be that one little thing in the middle of the night, trust and you'll wake up and go "oh so and so said that" ' (Patient 5)
Importance of carers being able to access support	'When the hospital was in lockdown, they weren't allowing me in so there were things he was told he had to do that I didn't know about and didn't find out about until later on and that became a huge issue' (Carer 2)

participants described having one-on-one peer support provided to them by people they knew who had previously been treated for HNC to be of great benefit in meeting their information and support needs. Carers expressed their preference for practical sources of information to support the patients with their nutrition intake (e.g., meal ideas). Accessing information and support from healthcare professionals was challenging for many carers and further compounded by COVID restrictions, limiting their access to hospital appointments with the patient.

Trigger film workshop priorities

Fifteen staff members participated in the staff event to show the video of patient and carer experiences. Two staff members and two patients attended the joint patient, carer and staff event. Improving access to existing resources and improving access to information from each discipline within the multidisciplinary team and patient and carer experiences within the hospital website were the two fundamental areas that were prioritised.

Co-design workshops

Three staff members and three patients attended the first workshop, and three patients and one carer attended the second workshop. At the end of the second workshop, participants had identified the need for a portal specifically for HNC patients to be made available on the hospital website that includes a link to existing reputable resources, including Head and Neck Cancer Australia and the Cancer Council.[19,20] To address additional information and support needs for patients and carers, workshop participants drafted a framework outlining information and support they would like developed by each member of the HNC multidisciplinary team. Their preference was for this information to be available online on the hospital website in both written (i.e., one-page fact sheet) and audio formats (i.e., 5-min podcast or videoblog), with access to patient and carer stories relevant to each topic. Workshop participants felt that the use of videoblogs created by patients unable to voice could provide a means to share their experiences, including demonstrating ways to communicate through text to speak software. Four frameworks were developed to address different information and support needs from

healthcare professionals prior to treatment, during treatment, <5 years' posttreatment and >5 years' posttreatment. Table 4 provides an example of the framework for resource development to show information and support needs <5 years' posttreatment to prioritise for podcast and factsheet development by patients, carers and healthcare professionals.

DISCUSSION

The aim of this study was to identify ways to improve patient and carer access to information and resources to support nutrition intake and other supportive care needs throughout HNC treatment and the survivorship period. Using EBCD enabled healthcare professionals, patients and carers the opportunity to participate in equal partnership in co-designing a framework for resource development.

Consistent with findings from previous studies, patients and carers expressed their preference for one-on-one meetings with healthcare professionals to address their information and support needs.[21] However, many acknowledged how difficult it was to retain information provided in these meetings. One-on-one support from healthcare professionals is recognised as a limited resource due to consultations being provided within scheduled times and information provided being restricted to the discipline of the healthcare professional.[21] Furthermore, many carers feel they are unable to ask for information themselves to prioritise the patient's needs.[22] In our study, patients, carers and healthcare professionals emphasised the importance of information consistency across the HNC multidisciplinary team. However, some healthcare professionals were unsure of where to refer patients and carers to find information if it did not relate specifically to their discipline, and patients and carers described searching for information online independently without being directed by healthcare professionals. A previous qualitative study by Findlay et al. reported that patients and carers described their care throughout HNC as having to 'navigate complex systems to meet their significant care needs'.[23]

Seeking health information online has become increasingly popular with the ease of access to information on the internet.[24] Studies have found that web-based programmes provide a means to communicate information that can be tailored to meet the needs of patients and carers.[25] Being able to access information online has been shown to empower patients to play a more active role in disease management and communicate with healthcare professionals more effectively.[26] However, limited levels of health literacy are a barrier to online sources of health education.[27] Studies have shown that people with lower levels of health literacy trust lower-quality information available on social networks in comparison to information provided to them by healthcare professionals.[27] Our study highlights the significant role healthcare professionals can play by directing patients and carers to sources of high-quality information. Furthermore, the use of instructional materials to increase access to and use of online health information has been shown to improve the eHealth literacy levels of participants.[28]

TABLE 4 Framework for resource development <5 years' posttreatment

Surgeon	Radiation oncology	Medical oncology
• Initiation of a follow-up plan to meet individuals' needs	• Osteoradionecrosis • Initiation of follow-up plan	• Initiation of follow-up plan
Dentist	Dietitian	Speech pathology
• Long-term dental care after HNC • Osteonecrosis and how to avoid this	• Enjoyment of food beyond taste • Long-term eating plan • Ways to experiment with food	• Speech, swallow and jaw exercises
Physiotherapist	Psychology	Social work
• Posttreatment fitness 'The dark time' • Rehabilitation – get strong early • Fitness – when can I start? • Targeted exercises identified to have a plan in place • Lymphoedema management	• Getting ready for first PET scan • Survivorship – living with a cancer diagnosis versus being cancer free	• Returning to work • Financial issues
Patients	Carers	Extra information
• What does the new normal look like?	• Managing compassion fatigue • How are you? • Tips to look after yourself	• Awareness of increased risk of skin cancer on radiation-affected areas • Lifestyle information (socialising again)

Abbreviations: HNC, head and neck cancer; PET, positron emission tomography.

Where patients and carers have limited access to the internet, healthcare professionals can provide a key role in guiding the patient through the available resources and downloading written material for them.[28] Our study also highlighted the importance of ensuring that reputable sources of information are made available through the hospital website to make it easier for healthcare professionals, patients and carers to refer to.

An EBCD study by Brady in 2020 found that patients with HNC desire information presented in a timeline to gain a better understanding of symptom onset, duration and management.[29] Similarly, we found patients and carers desired having access to information and support relevant to their needs prior to the start of the treatment, throughout treatment and in the early and later stages of survivorship. For patients and carers this included being able to learn more from the experiences of others who had been through HNC treatment, with some wanting to share their own experiences to help others. In addition to referring to existing HNC resources and peer support groups, our study identified novel ways to meet the needs of patients, carers and healthcare professionals through the development of a series of 5-min podcasts presented by patients, carers and healthcare professionals prior to the commencement of treatment, throughout treatment and extending into the survivorship period at 1 and 5 years posttreatment completion. Podcasts are recognised as an emerging form of education and teaching, allowing users to pause, rewind and relisten to information at their own pace.[30]

Although the EBCD toolkit was an invaluable resource, we found it challenging at times to work out the best way to apply the resources available in the toolkit in each workshop. Being able to refer to EBCD examples provided as case studies was helpful to understand how workshops were run in previous studies. A recent systematic review highlighted inconsistencies in the reporting of EBCD studies.[31] Although development, implementation and evaluation of resources are incomplete, our study aimed to provide readers with a clear outline of each step of the EBCD process based on recommendations for reporting EBCD studies.[31] A strength of our study was the level of interest patients, carers and healthcare professionals expressed in wanting to collaborate to make improvements in service delivery. This was reflected in participant numbers in interviews in step 2 of the study, with interviews being conducted at times suitable to each individual participant, with many patient and carer interviews conducted outside of working hours. However, a limitation of our study that has been reported in previous EBCD studies[29] was low participant numbers in our group event and co-design workshops that were conducted within working hours. Without funding to backfill clinical caseloads, healthcare professionals found it challenging to attend scheduled events. Many patients and carers invited to participate were also unable to attend due to work or other commitments. It is important to note that it was challenging to recruit carers to attend face-to-face group co-design events. Previous studies have shown that many carers dismiss their own concerns and needs to prioritise those of the patient.[22] This is also recognised as a limitation in the strength of areas prioritised in the group events and outputs from co-design workshops. Evaluation of the EBCD process will provide insight into barriers to participant engagement in the co-design step. We also recognise that COVID restrictions in place throughout the study period may be a limitation to patients and carers attending face-to-face co-design workshop events.

The co-design workshops revealed that all participants had high levels of digital health literacy. Although personas were created in the co-design workshops to consider the experiences of other patients and carers from different situations, this is a limitation of this study and reinforces the need to continue with the EBCD process to pilot and refine the interventions with a broader cohort of HNC patients and carers. A further limitation of this study was the lack of participant demographic information collected to enable an understanding of how the experiences of participants vary by age, sex, cultural background and socioeconomic status. Work is ongoing to continue to implement areas prioritised. As part of the EBCD process, a celebration event will be planned with study participants.

CONCLUSION

Applying the first three steps of the EBCD method has enabled the co-design of a framework for resource development with patients, carers and healthcare professionals to improve access to information and resources to support nutrition intake and supportive care needs throughout HNC treatment and survivorship. We aim to ensure that resources developed are easily accessible to patients and carers by ensuring healthcare professionals within the HNC multidisciplinary team are provided with instructional materials to direct patients and carers to resources developed. We recognise the limitations in our study, including low participant numbers in co-design events. Through evaluation of project outcomes and the EBCD process, future projects will aim to address barriers and enablers to participant engagement in EBCD projects.

AUTHOR CONTRIBUTIONS

Conceptualisation: Joanne Hiatt, Teresa Brown, Judith Bauer and Merrilyn Banks. *Methodology*: Joanne Hiatt and Judith Bauer. *Data collection*: Joanne Hiatt. *Data analysis*: Joanne S. Hiatt and Adrienne Young. *Writing – original draft preparation*: Joanne Hiatt. *Writing – review and editing*: Joanne Hiatt, Teresa Brown, Adrienne Young, Judith Bauer and Merrilyn Banks. *Funding*

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

Ethics approval was obtained from the University of Queensland, Brisbane, Australia (2021/HE000323), and the Royal Brisbane and Women's Hospital Research and Ethics Committee, Brisbane, Australia (HREC/2020/QRBW/68942).

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The reporting of this work is compliant with PRISMA guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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INVITED REVIEW

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Nutritional screening in a cancer prehabilitation programme: A cohort study

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Abstract

Background: Cancer patients are often malnourished pre-operatively. The present study aimed to establish whether current screening was appropriate for use in prehabilitation and investigate any association between nutritional risk, functionality and quality of life (QoL).

Methods: This cohort study used routinely collected data from September 2020 to August 2021 from patients in a Prehab4cancer programme. Included patients were aged ≥ 18 years, had colorectal, lung or oesophago-gastric cancer and were scheduled for surgery. Nutritional assessment included Patient-Generated Subjective Global Assessment (PG-SGA) Short-Form and QoL with a sit-to-stand test. Association between nutritional risk and outcomes was analysed using adjusted logistic regression.

Results: From 928 patients referred to Prehab4Cancer service over 12 months, data on nutritional risk were collected from 526 patients. Pre-operatively, 233 out of 526 (44%) patients were at nutritional risk (score ≥ 2). During prehabilitation, 31% of patients improved their PG-SGA and 74% of patients maintained or improved their weight. Odds ratios (OR) with confidence intervals (CI) showed that patients with better QoL using EuroQol-5 Dimensions (OR = 0.05, 95% CI = 0.01, 0.45, $p = 0.01$), EuroQol Visual Analogue Scale (OR = 0.96, 95% CI = 0.93, 1.00, $p = 0.04$) or sit-to-stand (OR = 0.96, 95% 0.93, 1.00, p = 0.04) were less likely to be nutritional at risk.

Conclusions: Almost half of patients in Prehab4Cancer programme assessed using PG-SGA were at risk of malnutrition. However, almost half of the sample did not have their risk assessed. Patients at risk of malnutrition were more likely to have a poorer QoL and sit-to-stand test than those who were not at risk.

KEYWORDS

cancer, cellular and physiological function, disease/therapeutic areas, malnutrition, quality of life

Key points

Colorectal, lung or oesopho-gastric cancer patients referred to the Prehab4-Cancer service underwent a nutritional assessment. Almost half of patients assessed using the Patient-Generated Subjective Global Assessment (i.e.,

PG-SGA) were at risk of malnutrition. Patients at risk of malnutrition were more likely to have a worse quality of life and sit-to-stand test indicating reduced physical function than those who were not at risk of malnutrition. This indicates that optimising the nutritional status of cancer patients in the prehabilitation period can maximise the nutritional status, functionality and quality of life of patients.

INTRODUCTION

Globally, cancer is the leading cause of premature death[1] with approximately 19 million new incidences each year, and this is predicted to rise to 27.5 million new cases by 2040.[2]

In the UK alone, the number of people aged ≥ 65 years living with cancer is increasing annually[3] and is complicated further by the additional co-morbidities encountered in older people.[4] A cancer diagnosis can lead to changes in physical status, activity levels and emotional or cognitive decline.[5] This functional impact of cancer and subsequent surgical and oncological treatments places an enormous burden on individuals.[6]

Despite advancing techniques, morbidity and mortality rates following elective surgery remain high[7,8] and malnutrition in the pre-operative period is an independent risk factor.[9] Several prospective cohort studies indicate that surgical patients with malnutrition have poorer clinical outcomes, higher rates of readmission, longer hospital admissions and increased associated healthcare costs.[10,11] However, when weight loss is identified pre-operatively and attenuated with oral nutritional supplements, there are benefits in relation to overall nutritional status and clinical endpoints.[12,13] Perioperative malnutrition has also been shown to reduce the number of patients who are able to go on to receive neo-adjuvant treatments such as chemotherapy.[14]

Prehabilitation (commonly known as "prehab") is a process that prepares people with cancer for treatment following their diagnosis. It focuses on improving an individual's physical, nutritional and psychological health to promote resilience throughout treatment and thereafter.[15] The key elements of a prehabilitation programme include cardiovascular and strength training, nutritional optimisation and psychological support to prepare patients for the challenges of treatment and to improve post-operative recovery.[16]

Evidence suggests that this style of multimodal prehab reduces post-operative length of stay and allows patients to return to their functional baseline at an increased rate.[17] There is, however, a paucity of literature within prehab investigating nutritional screening and nutrition specific interventions.[18,19] Malnutrition is estimated to affect 65% of patients undergoing surgery for cancer treatment.[20] Patients who are malnourished are additionally compromised by changes in body composition, cancer cachexia, systemic inflammation, symptom burden and treatment side effects.[21] Consequently, it is prudent to identify these patients early in their cancer pathway to enable appropriate nutritional interventions to commence. This also aligns with the expert consensus, Global Leadership Initiative on Malnutrition (GLIM), which highlights the requirement for appropriate screening and diagnosis of malnutrition.[22] Subjective Global Assessment (SGA) has been modified to create the Patient-Generated Subjective Global Assessment-Short Form (PG-SGA-[SF]), which is a screening tool validated for use in people with cancer.[23,24]

Malnutrition not only influences clinical outcome and hospital length of stay but impacts on patients' overall quality of life (QoL) and function after surgery.[25,26] These are key issues for patients post-operatively, which have been identified by qualitative evaluation using interviews and focus groups.[27] Additionally, length of time to recover after surgery and rehabilitation were reported by patients as important factors to facilitate transition to their pre-illness health status.[27] Post-operative functionality is an indicator of rehabilitation and is often measured using handgrip strength, which is associated with malnutrition,[28] along with measures of dynamic physical performance tests, which include the chair stand test and timed up and go test.[29] Moreover, sit-to-stand time has been shown to be a valid and reliable measure of lower limb strength.[30]

The present study aimed to establish whether screening for nutritional risk during a prehabilitation programme is advantageous to enable triage of patients for nutritional interventions and if there is any association between nutritional risk, functionality and quality of life.

METHODS

The present study is a cohort study using data that were collected as part of clinical practice in the Prehab4Cancer prehabilitation and recovery programme. The Prehab4-Cancer programme[31] was launched in April 2019 and aimed to provide system level prehabilitation for Greater Manchester cancer patients with colorectal, lung or oesophago-gastric cancer. Data included in the present study were collected between September 2020 and August 2021. Patients were included if they were diagnosed with cancer, registered with a General

Practitioner in one of the 10 Greater Manchester boroughs, were aged ≥ 18 years, had either colorectal, lung or oesophago-gastric cancer and were being offered curative surgery in a Greater Manchester National Health Service hospital. All 10 hospitals in Greater Manchester could refer patients into the prehabilitation service if they met the inclusion criteria described above. Referrals were accepted from all members of the multidisciplinary team working in colorectal, lung or oesophago-gastric surgical oncology or general practice teams within Greater Manchester localities.

Setting

Initially the setting for Prehab4Cancer was community-based localities including gyms and health centres. However, from March 2020, as a result of the COVID-19 pandemic, the service delivery transitioned rapidly from face-to-face contact to remote 'virtual' format. The setting for the service was therefore patient's homes or place of residence in the community for the duration of data collection for this cohort study. At this point, the PG-SGA (SF) was introduced and has been the primary nutritional screening tool used within the Prehab4Cancer and recovery programme. Following COVID-19 restrictions, the assessment of participants, and their access and receipt of the service were all delivered remotely.

Exposure

The purpose of the Prehab4Cancer and recovery programme was to provide exercise interventions, nutritional screening, nutritional advice and wellbeing support to people diagnosed with cancer, residing in Greater Manchester before, during and after their cancer treatment. Stakeholders were engaged from all the relevant clinical multidisciplinary teams across the region and agreement was made for patients to be referred at the point cancer surgery was planned using a single point of access. A full description of the overall service implementation has been provided by Moore *et al.*[31]

For nutritional screening, the first four boxes from PG-SGA(SF) including weight history, food intake, symptoms and activities combined with function designed for patients to self-screen were completed. The PG-SGA(SF) was used to triage patients into low, moderate or high risk of malnutrition. Patients deemed low risk (PG-SGA[SF], score 0-1), were provided with a Prehab4Cancer diet sheet designed by the Prehab4Cancer Greater Manchester nutrition group. Patients who were assessed as moderate risk (PG-SGA[SF], score 2–3) were provided with an 'Eating help yourself' booklet produced by dietitians at The Christie hospital. Those patients deemed to be high risk of malnutrition (PG-SGA[SF], score ≥4) were also provided with the 'Eating help yourself' booklet plus the exercise specialists escalated back to the referring clinical team. Escalation to the referring team was usually undertaken by liaising with the cancer nurse specialist supporting the patient at the hospital where surgery was scheduled. The cancer nurse specialist then referred individuals for specialist dietetic or medical assessment or intervention. In some instances, the Prehab4Cancer team could contact named specialist dietitians directly and this was the arrangement for patients with oesophago-gastric cancer who were referred to the oesophago-gastric centres in Greater Manchester with dietetic support.

Data collection

Level 4 Prehab4Cancer qualified exercise specialists within the core delivery team collected data at four assessment points; start of rehab, pre-operatively, post-operatively and at the end of rehabilitation. Patient's characteristics and clinical details were collected from initial referrals. The PG-SGA(SF) were completed remotely based on patient's memory recall from their hospital visit or measured using a range of domestic weighing scales. Sit-to-stand tests, aiming to assess functionality, were collected by self-report from patients with instructions from the core delivery team remotely. EuroQol Visual Analogue Scale (EQ-VAS) and EuroQol-5 Dimension Scale (EQ-5D) were recorded via the telephone or a video platform.

Follow-up

The nutrition screening tool was completed remotely at follow up with patients (via a phone or video call) as required by COVID-19 restrictions. The Prehab4Cancer exercise specialists recorded scores from the PG-SGA (SF) within the bespoke database for the programme 'Refer-All'. The PG-SGA(SF), EQ-5D, EQ-VAS and sit-to-stand test were recorded at each assessment time point.

- Assessment 1: Initial assessment – Start of prehabiliation phase
- Assessment 2: Pre-operatively/treatment – End of prehabilitation phase
- Assessment 3: Post-operatively/treatment – Start of rehabilitation phase
- Assessment 4: End of rehabilitation

The time between each of these assessment points varied and was based on the individual's cancer pathway. The points in the pathway included: diagnosis, referral, initial assessment, prehabilitation, surgery and rehabilitation. Rehabilitation commenced when participants were 'fit', and it was safe for them to

engage post-operatively. The time to rehabilitation post-operatively varied but was a maximum of 12 weeks. The time in prehabilitation also varied, which was based on cancer type and individuals' circumstances. Participants with oesophago-gastric cancer have a prolonged period of prehabilitation, when receiving neo-adjuvant chemotherapy that could be scheduled for up to 3 months, pre-operatively. The prehabilitation phase for patients with lung and colorectal cancer was normally shorter.

Statistical analysis

Survey responses were transferred into Excel (Microsoft Corp.) and then analysed using the SPSS, version 25.0 (IBM Corp.),[32] figures were generated using R Studio, version 1.3.1056 (https://www.rstudio.com).[33] The mean ± SDdeviations or frequencies and percentages were used to present the characteristics of patients. Outcome variables (EQ-VAS, EQ-5D and sit-to-stand) along with type of cancer were investigated in a logistic regression model to identify their impact on PG-SGA score and change in weight at assessment one, two and three. Assessment one was considered the baseline, and the findings from assessment four (i.e., end of rehabilitation) were not included due to the small sample size. The logistic regression model was first assessed unadjusted and then adjusted for potential confounders (age and gender) chosen a priori. Results were reported as odds ratios (OR), or adjusted odds ratios (aOR) and 95% confidence intervals (95% CI). Chi-squared was used to assess whether the proportion of patients who gained weight before versus after prehabilitation arose by chance. All appropriate goodness of fit and model assumptions were checked, and sensitivity analyses tested the robustness of the independent associations to additional confounding.

Sample size

Data were collected as part of clinical practice and therefore a sample size estimate was not undertaken. The size of the sample was therefore pragmatic based on an analysis of all participants referred to the service within the given period with complete datasets.

Ethical and data management

Healthcare practitioners collected data as part of routine clinical practice and therefore this study was exempt from formal ethical approval. For data management, the principles of good practice for data management outlined by Manchester Foundation Trust Research and Innovation team were followed along with appropriate governance procedures. All analyses were undertaken on unidentifiable data. Data were stored on a protected shared drive only accessible to those undertaking the analysis.

RESULTS

Characteristics of patients in the sample

In total, 928 patients were referred to the Prehab4Cancer service over 12 months. Patients were excluded from this

TABLE 1 Socio-demographic characteristics of 526 cancer patients assessed pre-operatively using the Patient-Generated Subjective Global Assessment.

	Number (%) of patients
Age (years)	
<50	25 (4.8)
51–60	96 (18.3)
61–70	179 (34.0)
71–80	190 (36.1)
81+	36 (6.8)
Gender	
Male	300 (57.0)
Female	226 (43.0)
Body mass index	
Male	27.5 (5.3)
Female	27.3 (6.7)
District	
Bolton	57 (10.8)
Bury	41 (7.8)
Manchester	101 (19.2)
Oldham	34 (6.5)
Rochdale	44 (8.4)
Salford	43 (8.2)
Stockport	56 (10.6)
Tameside	58 (11.0)
Trafford	41 (7.8)
Wigan	51 (7.8)
Type of cancer	
Colorectal	228 (43.3)
Lung	238 (45.2)
Upper gastrointestinal	60 (11.4)

analysis if they did not enrol in the programme ($n = 71$) or did not have the PG-SGA(SF) completed ($n = 331$). At assessment 1, there were 526 patients with a cancer diagnosis from across Greater Manchester with a PG-SGA score. Out of these patients, 57% were male, mean age was 68 years and patients had been diagnosed with either colorectal (43.3%), lung (45.2%) or oesophago-gastric cancer (11.4%) (Table 1).

PG-SGA

Assessments at time points 1 and 2 were undertaken prior to the operation; assessments 3 and 4 were conducted post-operatively. PG-SGA(SF) was assessed at each assessment and patients were considered at risk of malnutrition if they had an additive score ≥2 (Table 2). The number at risk of malnutrition at the initial assessment was 233 (44.3%); at assessment 2, this was 82 (41.3%); post-operatively, at assessment 3, 68 (62.4%) participants were at risk of malnutrition; however, by assessment 4, only four patients (20%) were at risk of malnutrition. Almost one-third of patients (30.8%) improved their PG-SGA(SF) score between assessments 1 and 2. An additional 15.6% of patients were considered not at risk of malnutrition at assessment 1 and maintained this status at assessment 2.

There were 293 patients with a baseline PG-SGA (SF) score between 0 and 1 and so were assessed not to be at risk of malnutrition. The remaining 233 patients with a baseline PG-SGA(SF) score ≥ 2 required some form of intervention and were at risk of malnutrition. Results of EQ-VAS, EQ-5D and sit-to-stand test from each assessment along with type of cancer were included in a logistic regression model to assess their impact on the likelihood of predicting patients being at risk of malnutrition. A logistic regression analysis shows that model 1 was statistically significant compared to the null model ($\chi^2 = 59.7$, d.f. = 5, $p < 0.001$), explaining 27.8% of the variation of PG-SGA(SF) score (Nagelkerke R^2) and correctly predicted 57.2% of cases. Table 3 shows that a higher EQ-5D score (indicating a better health related quality of life) at all assessments was associated with a reduction in the likelihood of being malnourished at assessment 1. A higher EQ-VAS score (indicating a better health related quality of life) at assessment 1 was associated with a reduction in the likelihood of being malnourished at baseline. A higher sit-to-stand test (indicating a greater level of strength) at assessments 1 and 2 was associated with a reduction in the likelihood of being malnourished at baseline after adjusting for age and gender. In addition, patients with oesophago-gastric cancer were almost six times more likely to be malnourished compared to patients with colorectal cancer at baseline after adjusting for age and gender.

Change in weight

Weight loss was also considered a predictor of malnutrition; 25.1% of patients lost weight in the 4 weeks prior to assessment 1, and 42.7% of patients lost weight in the 6 months prior to assessment 1. After attending assessment 1, most patients subsequently gained (26.7%) or maintained (47.6%) their weight until their operation (assessment 2). Figure 1 shows how patients' fluctuate in weight before and after assessment 1 regardless of cancer type. A chi-square test of independence was performed to examine the relation between weight change (gained, maintained or lost) before and after assessment 1 (4 weeks before vs. assessment 2, which occurred a mean of 6 days after assessment 1). The relation between these variables was significant ($\chi^2 = 24.5$, d.f. = 4, $p < 0.001$; $n = 188$), such that patients were more likely to gain

TABLE 2 Patient-Generated Subjective Global Assessment Score (PG-SGA) at assessment time points one to four

	Triage recommendation	Assessment time point			
PG-SGA additive Score		Time 1, *n* (%) *n* = 526	Time 2, *n* (%) *n* = 198	Time 3, *n* (%) *n* = 109	Time 4, *n* (%) *n* = 20
0–1	No intervention required at this time. Re-assessment on routine and regular basis during treatment.	293 (55.7)	116 (58.6)	41 (37.6)	16 (80.0)
2–3	Patient and family education by dietitian, nurse, or other clinician with pharmacological intervention as indicated by symptom survey and lab values as appropriate	96 (18.3)	45 (22.7)	29 (26.6)	3 (15.0)
4–8	Required intervention by dietitian, in conjunction with nurse or physician directed by symptoms	96 (18.3)	28 (14.1)	30 (27.5)	1 (5.0)
≥ 9	Indicates a critical need for improved symptom management and/or dietetic intervention	41 (7.8)	9 (4.5)	9 (8.3)	0 (0)

TABLE 3 Logistic regression to show the impact of being at risk of being malnourished at baseline on patients at assessments 1, 2 and 3.

	Model 1 Assessment 1 $n = 257$ OR (95% CI), p	**Model 2 Assessment 1 $n = 257$ aOR (95% CI), p**	**Model 3 Assessment 2 $n = 140$ aOR (95% CI), p**	**Model 4 Assessment 3 $n = 73$ aOR (95% CI), p**
EQ-VAS	**0.97 (0.95–0.99), 0.02**	**0.97 (0.95–0.99), 0.01**	1.00 (0.96–1.04), 0.97	1.03 (0.98–1.09), 0.27
EQ-5D	**0.03 (0.00–0.26), 0.001**	**0.05 (0.01–0.45), 0.01**	**0.02 (0.00–0.39), 0.01**	**0.01 (0.00–0.73), 0.04**
Sit-to-stand	0.97 (0.93–1.01), 0.06	**0.96 (0.93–1.00), 0.04**	**0.94 (0.90–0.99), 0.02**	0.94 (0.86–1.03), 0.18
Cancer site:				
Colorectal (ref)				
Lung	1.31 (0.71–2.44), 0.39	1.18 (0.62–2.24), 0.61	0.87 (0.36–2.09), 0.75	1.22 (0.36–4.12), 0.75
Upper gastrointestinal	**5.75 (2.28–14.52), < 0.001**	**5.96 (2.22–15.96), < 0.001**	3.19 (0.86–11.80), 0.08	3.57 (0.23–54.54), 0.36
Age (years)				
81+ (ref)				
71–80		1.22 (0.21–7.13), 0.83	0.38 (0.13–10.91), 0.58	4.83 (0.19–120.72), 0.34
61–70		0.92 (0.25–3.46), 0.90	0.82 (0.14–4.83), 0.83	1.57 (0.12–19.95), 0.73
51–60		1.22 (0.36–4.18), 0.75	1.43 (0.28–7.30), 0.67	1.03 (0.10–11.01), 0.98
<51		0.52 (0.15–1.74), 0.29	0.64 (0.14–2.97), 0.57	0.65 (0.06–7.13), 0.72
Gender				
Male (ref)				
Female		1.76 (0.93–3.30), 0.08	2.01 (0.86–4.68), 0.11	1.67 (0.48–5.79), 0.42

Models 2, 3 and 4 were adjusted for age and gender. Model 1 and 2 used data from assessment 1, model 3 used data from assessment 2 and model 4 used data from assessment 3. *$p < 0.05$. CI, confidence interval of odds ratio; EQ-VAS- EuroQoL Visual Analogue Scale; EQ-5D, EuroQoL 5 Dimension; ref, reference category; OR, odds ratio; aOR, adjusted odds ratio.

weight after attending assessment 1 compared to the 4 weeks prior to assessment 1 (see Table S1). Assessment 2 represented the time before the operation and is likely to explain the weight loss identified in most patients between assessment 2 and assessment 3.

A second logistic regression model was conducted to evaluate how each outcome (EQ-VAS, EQ-5D, sit-to-stand and cancer type) influenced the likelihood of a patient experiencing weight loss in the 6 months prior to assessment 1. In the 6 months before starting prehabilitation, 209 patients gained or maintained their weight, whereas 281 patients had lost weight. A logistic regression analysis found that model 2 was statistically significant when compared to the null model ($\chi^2 = 14.0$, d.f. = 5, $p = 0.02$), explained 8.0% of the variation of weight loss (Nagelkerke R^2) and correctly predicted 62.5% of cases. Table 4 shows that after adjusting for age and gender patients with a higher EQ-5D score at assessment 1 were more likely to have gained or maintained their weight in the 6 months prior to assessment 1. Table 4 also shows that the type of cancer has no impact on the likelihood of a patient losing weight in the 6 months prior to assessment 1. In addition, patients under the age of 70 years were less likely to have lost weight in the 6 months before assessment 1 compared to patients over the age of 81 years.

DISCUSSION

There were 44.3% of patients at risk of malnutrition at assessment 1 identified from the PG-SGA(SF). It is evident in the literature that malnutrition is a strong risk factor for complications during and after surgery, including increased levels of mortality, morbidity and length of hospital stay.[10,11,20] However, it is recognised that malnutrition is one of the few modifiable risk factors pre-operatively.[34] Unintentional weight loss, which is a measure used to calculate the PG-SGA(SF), has been directly associated with functional impairment, decreased immune defences, delayed wound healing and organ dysfunction.[35] Interestingly, people after cancer reported a poor nutritional status affected their energy levels, rehabilitation, psychosocial and overall quality of life after surgery.[36] The prehabilitation phase therefore provides a critical time to maximise patient's physical and psychological health to optimise outcomes in preparation for surgical procedures. Incorporating a nutrition-screening tool into prehabilitation is therefore essential.

Almost one third of participants improved their PG-SGA(SF) score in the prehabilitation period following the protocol for triaging nutritional support interventions. This is not surprising because trials have

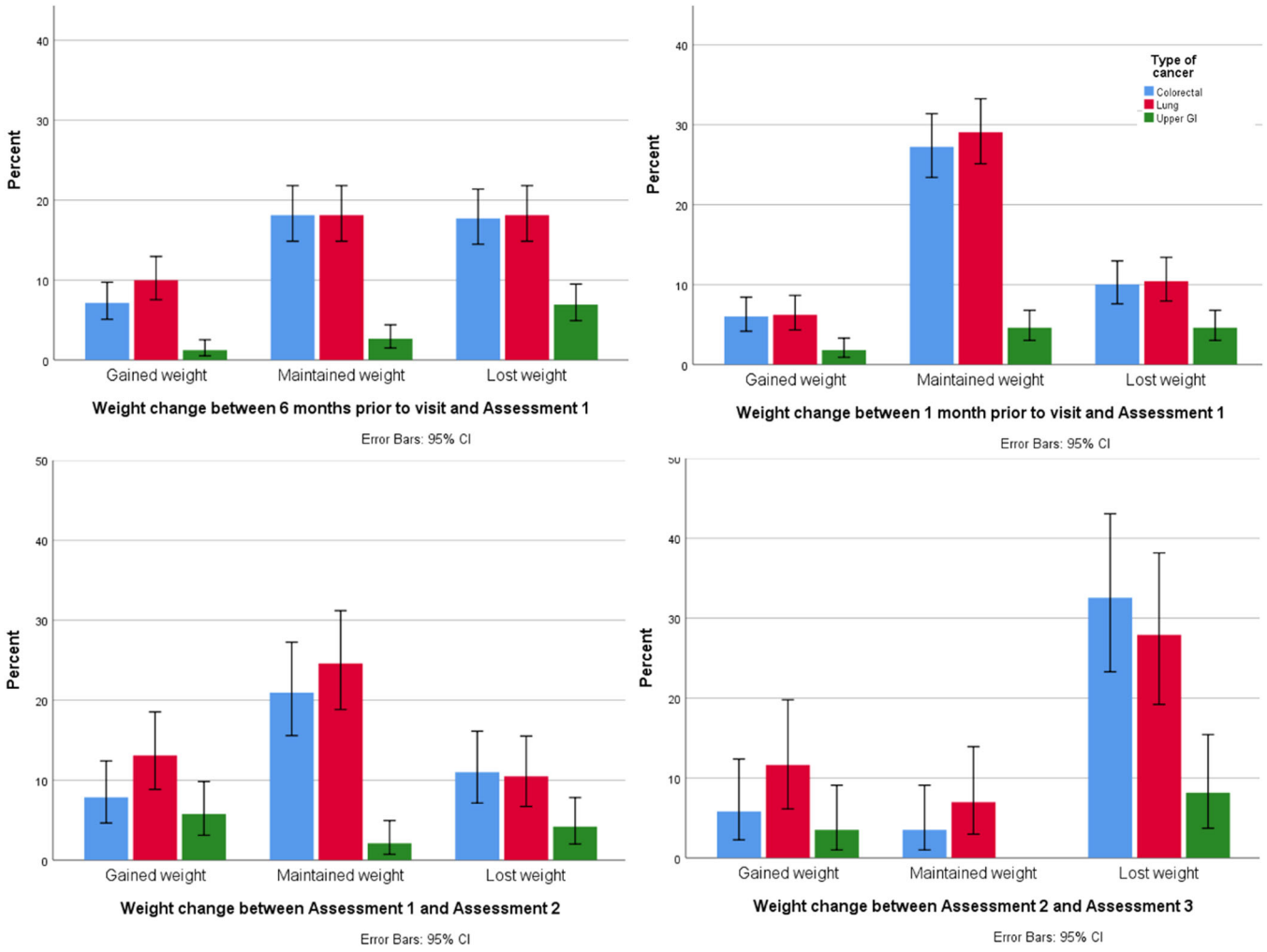

FIGURE 1 Change in weight pre- and post-operatively for patients with colorectal, lung and oesophago-gastric (OG) Cancer

demonstrated that when malnutrition or unintentional weight loss is treated pre-operatively nutritional status is improved and positive outcomes reported in terms of complications and quality of life.[12,37] In addition, most patients (74.3%) maintained or gained weight between assessment 1 and assessment 2. The results show that patients were more likely to improve their nutritional status compared to the weeks preceding initiation of prehabilitation. These findings demonstrate that nutrition screening, as part of a prehabilitation programme is beneficial at identifying risk and then informing the delivery of appropriate nutritional interventions in a real-world clinical environment.

Over half of the participants were at risk of being malnourished after surgery. This is an important finding indicating that the provision of nutritional support interventions are important in the rehabilitation phase as well as prehabiliation. There is a clear drop off in the number of patients attending each of the assessments, with only 20 patients completing all four assessments. This reflects the ongoing nature of the programme with a large number of patients still enrolled and awaiting future assessments.

The PG-SGA(SF) has previously been validated to assess and identify malnutrition in patients with cancer.[23] The present study adds to the current knowledge base by demonstrating that PG-SGA(SF) can effectively triage patents with cancer to specific interventions. The nutritional interventions were delivered by a multidisciplinary team across many healthcare localities, and were aimed at preventing weight loss and reducing the risk of malnutrition with the purpose of optimising health status of patients going into surgery. However, almost half of the patients referred to the Prehab4Cancer programme were not screened for risk of malnutrition. The completion of PG-SGA(SF) required actual weight and weight from the previous 3–6 months. However, because the data collection took part during the pandemic, people without home scales could not visit a relative's house to be weighed or a local chemist or general practitioner's surgery. The main reason given

TABLE 4 Logistic regression to show the impact of weight loss within the previous six months compared to assessment 1 on patients at assessments 1, 2 and 3

	Model 1 Assessment 1 $n = 232$ OR (95% CI), p	**Model 2 Assessment 1 $n = 232$ aOR (95% CI), p**	**Model 3 Assessment 2 $n = 128$ aOR (95% CI), p**	**Model 4 Assessment 3 $n = 64$ aOR (95% CI), p**
EQ-VAS	0.991 (0.97–1.01), 0.37	0.99 (0.97–1.01), 0.26	0.97 (0.93–1.01), 0.18	1.00 (0.94–1.06), 0.98
EQ-5D	0.14 (0.02–1.06), 0.06	**0.11 (0.01–0.98), 0.05**	0.53 (0.03–9.27), 0.66	1.08 (0.00–318.46), 0.98
Sit-to-stand	0.99 (0.96–1.02), 0.45	1.00 (0.97–1.04), 0.94	1.03 (0.98–1.08), 0.22	1.02 (0.93–1.12), 0.63
Cancer site				
Colorectal (ref)				
Lung	0.69 (0.37–1.28), 0.24	0.63 (0.33–1.20), 0.16	0.52 (0.21–1.27), 0.15	0.62 (0.17–2.34), 0.48
Upper gastrointestinal	1.89 (0.79–4.52), 0.15	2.10 (0.85–5.19), 0.11	2.18 (0.61–7.77), 0.23	
Age (years)				
81+ (ref)				
71–80		0.23 (0.04–1.41), 0.11		0.67 (0.02–26.07), 0.83
61–70		**0.12 (0.03–0.53), 0.01**	0.21 (0.04–1.27), 0.09	0.15 (0.01–3.36), 0.23
51–60		**0.14 (0.04–0.52), 0.004**	0.21 (0.04–1.03), 0.06	0.10 (0.01–2.05), 0.14
<51		**0.15 (0.04–0.59), 0.01**	0.30 (0.07–1.31), 0.11	0.17 (0.01–3.19), 0.24
Gender				
Male (ref)				
Female		1.16 (0.62–2.18), 0.65	2.07 (0.87–4.89), 0.10	3.01 (0.82–11.05), 0.10

Models 2, 3 and 4 were adjusted for age and gender. Model 1 and 2 used data from assessment 1, model 3 used data from assessment 2 and model 4 used data from assessment 3. *$p < 0.05$. CI, confidence interval of odds ratio; EQ-VAS, EuroQoL Visual Analogue Scale; EQ-5D, EuroQoL 5 Dimension; ref, reference category; OR, odds ratio; aOR, adjusted odds ratio.

for missing data here was unknown weight and weight recall. Methods of collecting weight data were explored within the Prehab4Cancer team and one suggestion was to provide vulnerable older people with digital scales. Conversely, surrogate markers for weight, including loose fitting clothes, decreasing a dress size or collar size, loosening trousers or tightening of belts notches, have been considered. Other tools that do not require an actual weight would also be an option including the Paperweight Armband or the Modified Patient Association Checklist.[38,39] Nutritional assessment and dietary interventions for housebound vulnerable adults have been previously identified as a priority area for research[40]

Patients with upper gastrointestinal cancer were six times more likely to be malnourished compared to patients with colorectal cancer.[41] In addition, older patients were more likely to have lost weight in the 6 months prior to prehabilitation compared to younger patients. Given these differences, future practice should reflect these finding so that both older patients and those diagnosed with upper gastrointestinal cancer are offered more intense prehabilitation to optimise their nutritional status pre-operatively. Additional dietetic resources were available for patients with upper gastrointestinal cancer prior to surgery in the present study, which may have contributed to such positive results. However, dietetic interventions may not have been implemented in a timely manner, which could have been improved by dedicated time within the prehabilitation service. Other studies have shown benefits of nutritional support in upper gastrointestinal cancers and nutritional interventions have recently been reviewed highlighting clinical and nutritional benefits during the perioperative period in gastrointestinal surgery.[13,42]

Despite these promising findings, 52.5% of patients maintained and 16.7% of patients increased their PG-SGA(SF) score during the prehab phase, demonstrating no improvement and a possible deterioration. This may reflect the lack of time and scope for interventions to be delivered, as the timelines were dependent on the cancer site and on surgical schedules. It may be beneficial to extend the prehab phase to maximise outcomes further, where possible, without delays to surgical interventions. In addition, dedicated nutrition Prehab4Cancer staff would be a considerable advantage to initiate and follow up patients at risk of malnutrition within a timely fashion. However, these results show some positive outcomes from nutritional screening and the implementation of a triage system that can sign post to different nutritional interventions as appropriate. Another limitation is that there were no screening

scores on a large proportion of patients who were referred and assessed at prehabiliation. Further investigation is required to understand why patients did not undergo screening. This was not formally documented as part of the service delivery, and so would be a useful addition to future evaluations and data collection. In addition, the extent of dietary advice and nutritional support interventions provided as a result of screening is unknown and this is an area that would benefit from further research.

These data were collected during the COVID-19 pandemic and so are reflective of service modifications that were made according to public health advice for the data collection period. During the pandemic, many patients opted for home delivery of prehabilitation, which may affect the data in relation to service uptake and engagement levels.

These findings are from a clinical service covering a large geographical area in the North of England including both male and female patients with different demographic backgrounds, socio-economic groups and ages. The PG-SGA(SF) tool has been reported as being accurate, sensitive and specific at diagnosing malnutrition[43]; therefore, this tool can be used with other cancer patients across the UK to identify and triage patients. However, only patients with either lung, colorectal or upper gastrointestinal cancer were included in the present study. Given the nature of the assessment, patients with a cognitive impairment such as dementia or those who are unable to read or write were excluded. In addition, the results are limited because they did not include people who could not speak English, and so the findings are not necessarily generalisable to all ethnic groups.

The triage system for this service focused on risk of malnutrition addressing primarily undernutrition. Malnutrition includes both under and over nutrition and further service developments may include addressing issues such as sarcopenic obesity in cancer patients. Sarcopenic obesity indicates a reduced lean mass and increased fat mass creating a high risk body composition phenotype. A cancer diagnosis is described as a teachable moment[44] and presents an opportunity for healthcare professionals to provide sign posting for healthy eating and strengthening exercises to encourage weight reduction at the same time as maintaining muscle mass. Indeed, resistance exercises are important for all cancer patients and should be encouraged and supported when appropriate to maintain muscle mass and physical function.

The data presented provides new information on nutritional screening and a triage system. The findings suggest that PG-SGA(SF) can be used within a prehabilitation service and nutritional triaging is feasible within a real world environment. The results highlight a need for appropriate staffing resources to be able to implement a triage system and facilitate the provision of nutritional interventions where a risk of malnutrition is identified. The outcome data show that both quality of life and functionality are associated with nutritional status and, specifically, poorer quality of life and function are related to poorer nutritional status.

Further research is required to assess the impact of nutritional interventions delivered as a result of triaging and how the uptake of nutritional screening can be improved.

CONCLUSIONS

This service evaluation shows that the PG-SGA(SF) tool is easy to use in a virtual setting and effectively triages patients to receive the appropriate intervention. Prehabilitation is an important phase to maximise nutritional status, functionality and quality of life in patients with a diagnosis of cancer awaiting a surgical procedure. A longer prehabilitation period could be beneficial to maximise the impact of the intervention, particularly for patients with upper gastrointestinal cancers and older people who have been shown to be at a greater risk of malnutrition.

AUTHOR CONTRIBUTIONS

KRG, JM, SJH, RM, AR, KB collected the data at the Prehab4Cancer assessment time points, CF, STB analysed the data, NB, KO, KD, LG JM, KM, ZM were involved in setting up the service and the study. All authors contributed to the interpretation of findings and the writing of the manuscript.

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CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The lead author affirms that no important aspects of the study have been omitted. The original protocol had to be amended because of the exclusion of case–control studies and studies that assessed only physical activity, as a result of an excessive number of studies identified during the full-text screening search.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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'It's like being pushed into sea on a boat with no oars': Breast cancer survivorship and rehabilitation support in Ireland and the UK

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Abstract

Background: Cancer survivorship is associated with co-morbidities including anxiety, depression and cardiovascular disease (CVD). Rehabilitative care post-treatment is vital for survivors' psychological and physical well-being. The present study aimed to investigate breast cancer survivors' attitudes towards their health post-treatment; their awareness of co-morbidities associated with treatment; and their awareness of support systems available.

Methods: A qualitative research approach was employed, using semi-structured interviews with breast cancer survivors from the UK and Ireland. Data were analysed using thematic analysis. Eight breast cancer survivors were recruited through purposive sampling.

Results: Two themes emerged from the data: (1) health and rehabilitation post-treatment, which included mental and physical health and a desire to control one's own health in survivorship as well as a discussion around co-morbidities, and (2) access to support services in survivorship, which highlighted both positive and negative experiences of accessing support, as well as reasons for not accessing support in survivorship.

Conclusions: Access to rehabilitation support, including diet, exercise and stress management, is key to survivorship. Rehabilitation and support services need to be more readily available for survivors to aid them in this journey and to educate them on the increased risk of conditions such as CVD with cancer treatment. Utilising current cardiac rehabilitation models could be a solution to provide a holistic cancer rehabilitation, thus providing the lifelong support that cancer survivors both want and need.

KEYWORDS

cancer, cancer-journey, cardio-oncology, rehabilitation, survivorship

Key points

- Access to rehabilitation support, including diet, exercise and stress management, is key to survivorship; however, access to support differed and was lacking for many survivors.
- Longer-term comorbidities of cancer treatment were not fully understood. Therefore, there is a need for rehabilitation and support services to educate survivors on the increased risk of conditions such as cardiovascular disease with cancer treatment. These services must also address long-term risk through lifestyle factors, including diet and physical activity.

- Utilising current cardiac rehabilitation models could be a solution to provide a holistic cancer rehabilitation, thus providing the lifelong support that cancer survivors both want and need.

INTRODUCTION

Breast cancer is the most common cancer in the UK and Ireland, with more than 150 new UK diagnoses daily between 2016 and 2018.[1,2] Furthermore survival rates are increasing, with 5-year survival at 82% and 10-year survival rate at 76% in Ireland and the UK, respectively.[1,2] This increasing survivorship is important to consider because the treatment of cancer has a profound effect on both physical and psychological wellbeing, with acute side effects including nausea, fatigue and loss of physical fitness and chronic side effects including the development of comorbidities such as oesteoporosis and cardiovascular disease (CVD).[2] In an analysis of 2552 breast cancer survivors, 24% had at least one comorbidity at 5-year follow-up, with this increasing to 25% between 6 and 10 years.[3] The absolute risk of dying from CVD following breast cancer ranges from 1.6% to 10.4%[4] and this may be attributed to cardiotoxic effects of treatment such as radiotherapy, particularly if the heart is in the treatment field.[5] Radiation-associated cardiovascular-toxicity may be progressive, and thus survivors may still deal with the effects of their treatment years after its completion.

The transition from 'patient' to 'survivor', when such chronic conditions can begin to develop, may be a period of uncertainity. The routine of actively receiving treatment has been reported as a coping strategy for some patients that is lost once treatment has been completed.[6] The need to develop active behavioural strategies specifically for this transition, focusing on health practices, managing stress and coping with phsycial and psychological effects associated with cancer treatment, has been previously highlighted.[6] Smith *et al.*[7] reported that breast cancer survivors have a desire for information on lifestyle, nutrition and exercise support to promote their health and minimise risk of cancer recurrence, as well as access to available resources for ongoing support and counselling. Participants considered the most appropriate time to have this conversation to be toward the end of their treatment. Continuous care post-treatment is therefore vital for survivors' psychological and physical well-being.

Despite this, the after-care for breast caner survivors varies globally and there is no standardised national approach.[8] In 2009, Macmillan proposed a system of after-care that would include an end-of treatment assessment and risk stratification of the level of ongoing support likely to be needed by the survivor.[9] In the UK, threre is a nationwide service, Move More, which encompasses behaviour change and physical activity (PA) interventions and has been shown to increase PA, health-related quality of life (QoL) and fagitue in participants.[10] The need for a multidisciplinary team to offer support from the point of diagnosis throughout the cancer pathway was highlighted, as well as the need for cancer specific training for staff on such programs.

Despite a clear need for ongoing support, this is not always felt by survivors. A cohort of post-menopausal breast cancer survivors in Ireland raised concerns regarding survivorship care, with participants reporting to feel 'dismissed' when asking healthcare professionals (HCPs) for advice.[11] Some women felt that HCPs had not sufficiently informed them of the side effects experienced during survivorship. Additionally, women felt that medical reviews during survivorship were unsatisfactory and impersonal in nature.[11] These findings highlight the importance of educating patients of the chronic comorbidities of cancer, and the pscycho-social impact of the diagnosis and treatment as well as a survivorship strategy or post-care plan.[12] Little is known however about whether this is the experience of breast cancer survivors.

The present study aimed to investigate breast cancer survivors' attitudes towards their health post-treatment; their awareness of co-morbidities associated with their treatment, including CVD; and their awareness of support systems available.

METHODS

Sampling and recruitment

Participants ($n = 8$) in Ireland and the UK were recruited through Facebook groups for breast cancer survivors, as well as via Twitter and Instagram, between 6 January and 15 February 2021. The recruitment advertisement was shared 71 times; 42% of the shares came from Facebook, 52% from Twitter and 6% from Instagram. Guest *et al.*[13] reported that theoretical saturation can be achieved within the first six interviews; thus, the target sample size was set between six and 15 participants.

The study's inclusion criteria comprised: female breast cancer survivors; in remission for a minimum of 2 years; 18 years and older; a resident in Ireland or the UK; possessing a phone or computer with web browser access; and being willing to attend a recorded hour long interview at a time that was convenient to both themselves and the lead reseacher.

Participants were excluded from the research if they were unable to understand written and spoken English and/or if they had known or diagnosed CVD, type 1 or type 2 diabetes or chronic kidney disease, which was established at the stage of consent. These participants were excluded because of their potential increased awareness of CVD. Seventeen participants expressed an interest in the research; nine of the participants met the exclusion criteria and therefore did not participate in an interview.

Design

The research design was formulated following guidance by Moisey *et al.*[14] and Swift and Tischler.[15] The work followed an inductive and reflexive approach, thus acknowledging a relativist ontology. Participants were interviewed via Microsoft Teams (Microsoft Corp.) at a pre-arranged time. Online interviews were utilised as a result of Covid-19 restrictions and to allow for recruitment to occur from a wider sample of participants. A semi-structured interview guide was developed using open-ended questions and prompts. The interview was broken up into five sections: demographic information; the participants' breast cancer journey; the idea of health to a survivor; knowledge of comorbidities associated with cancer treatment; and knowledge of rehabilitation support for survivors. This allowed the researcher to identify and make connections between knowledge regarding the effects of an individual's treatment, as well as connections between geographical locations and access to services. The participants had 24 h to withdraw from the study once they had completed the interview. Following the interview, participants were directed to support groups including MacMillan and Breast Cancer Now, and information surrounding their health post treatment as well as recommendations surrounding a healthy diet and lifestyle in a follow-up email. Following a 24-h period, data were transcribed verbatim, using an AS-2400 Transcription Kit (Olympus). Ethical approval was granted by the institute's Research Ethics Committee in January 2021 (KT/JB/2021).

Data analysis

Data were thematically analysed using the five-step approach outlined by Braun and Clarke.[16] Thematic analysis aims to identify patterns of meanings and themes within a data set, which may be both implicit and explicit, thus providing the necessary groundwork for establishing models of human thinking, feeling and behaviour. This method of analysis acknowledges the importance of the prevalence of themes without sacrificing depth of analysis.[17] Familiarity of the data began with listening to individual transcripts before reading transcripts and checking for accuracy. Transcripts were then read line-by-line and initial codes were generated. These codes were then examined, and similar codes were clustered together to form candidate themes. These themes were then reviewed and refined to ensure that they reflected the coded extracts and the entire data set. Extracts to illuminate the themes and sub-themes were then selected. Ongoing reflexivity was practiced through discussions of emerging data, presentation and questioning of the data between the first and second investigator. These were then presented to the third investigator for further interrogation of the themes emerging. This process served to encourage dialogue, reflexivity and critique of interpretation of the data through peer-debriefing, hence ensuring trustworthiness, rigor and accuracy of the data.

RESULTS

Participant characteristics are shown in Table 1. Eight participants were recruited to the study. All participants were female, aged 45–64 years, had been diagnosed with

TABLE 1 Participant characteristics

	N
Age (years)	
45–49	1
50–54	1
55–59	2
60–64	4
Place of residence	
Cork, Ireland	1
Donegal, Ireland	1
Dublin, Ireland	1
Kilkenny, Ireland	1
Laois, Ireland	1
Bristol, UK	1
Chester, UK	1
Leeds, UK	1
Treatment course	
Lumpectomy	3
Lumpectomy including lymph node removal	2
Mastectomy	1
Bilateral mastectomy	2
Chemotherapy	4
Radiotherapy	4
Targeted biological therapy	3
Hormone therapy	5

breast cancer and received treatment in the UK or Republic of Ireland. Participants were included from both urban and rural locations. All participants received curative treatment for their breast cancer. The most common treatment pathway used among participants was hormone therapy, including tamoxifen and anastrozole, followed by chemotherapy and radiation. Six out of eight participants had surgery in their treatment pathway, with this ranging from a lumpectomy to bilateral mastectomies and reconstruction. Five of the six participants who had surgery received at least two other forms of treatment. Seven of the eight participants received more than one form of treatment. The treatment received by each participant is shown in Table 2.

The average length of interviews was 30 min, equating to 52 pages of transcript. Two themes (Figure 1) and six sub-themes were generated from the transcripts with illustrative quotes chosen for each (Table 1).

The core concept of holistic health and survivorship

The core concept that emerged was an individualised and holistic approach to health, focussing on mental and physical well-being. Survivors considered access to post-treatment rehabilitation support a core component of their survivorship care pathway, regardless of whether they had a negative or positive experience of accessing support in survivorship. A holistic approach to health involves a range of HCPs. This approach allows a patient to be assessed and treated by the HCP that are required to treat any co-morbidities or side effects of treatment following its completion; for example, a dietitian to treat chemo-induced malnutrition, a physiotherapist to aid movement following a mastectomy and a psychologist to provide support following the completion of treatment (Table 3).

One participant felt that where '*everything had fallen down*' in terms of the level of care received throughout their cancer journey was the aftercare following the completion of their treatment and at the beginning of their survivorship:

> It was like … being pushed into sea from shore on a boat with no oars … what now? What do I do? … I've had to do all this myself, and I don't think that's right

The participant felt that it was her 'own research' and 'determination' that enabled the investigation and

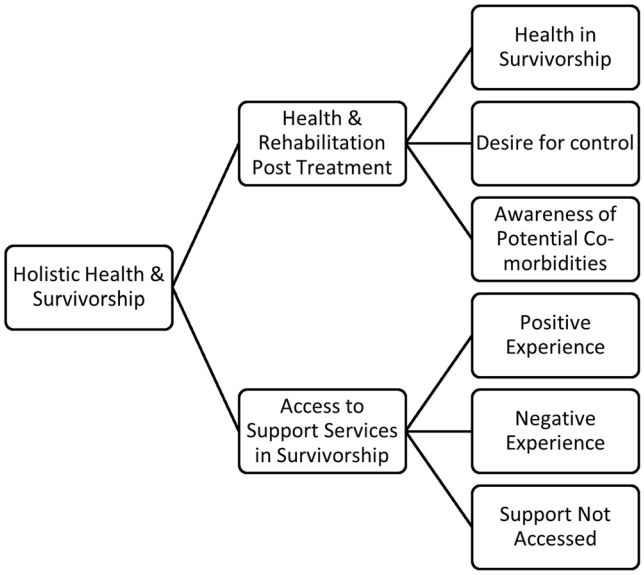

FIGURE 1 Themes generated from the data

TABLE 2 Treatment received by each participant

Participant	Treatment
1	Lumpectomy with lymph node removal, chemotherapy, radiotherapy, hormone therapy (tamoxifen)
2	Lumpectomy with lymph node removal, chemotherapy, targeted biological therapy (herceptin and pertuzumab) and hormone therapy (anastrozole)
3	Lumpectomy, chemotherapy, targeted biological therapy (herceptin)
4	Bilateral mastectomies and reconstruction
5	Radiotherapy
6	Lumpectomy, radiotherapy, hormone therapy (tamoxifen)
7	Lumpectomy, radiotherapy, hormone therapy (arimidex) full mastectomy and failed reconstruction
8	First diagnosis: chemotherapy, targeted biological therapy (herceptin and trastuzumab) Second diagnosis: double mastectomy, hormone therapy (letrozole and zoladex)

TABLE 3 Themes, sub-themes and illustrating quotes

Theme	Subtheme	Illustrating quote
1. Health and rehabilitation post-treatment	Health in survivorship	'*I was lucky that physically my rehabilitation was easy … but I suppose psychologically that's the area that is harder … It's a more complicated rehabilitation [the psychological] because it's about you know how you think and how you get back into your life and you know your attitudes to some things change … I suppose the counselling was the biggest part of my rehabilitation*' (P4)
		'*Rehabilitation for me means physical and psychological … going back to my full potential for my abilities in those areas … psychological one is a bit more difficult because everyone is different … it means going back to my physical abilities and my psychological wellbeing …*' (P1)
	Desire for control	'*I am determined to get back, but I mean whether I ever get back to what I was I don't know*' (P2)
		'*I am back in Pilates and I've changed from mat classes to reformer classes because its more on the muscle, its's more intense … I still don't drink and I don't smoke and we are very careful about the majority of foods*' (P3)
	Awareness of potential co-morbidities	'*… it was the fact that my fertility would be impacted … with the chemotherapy … and that was quite traumatic for me*' (P1)
		'*I'd read about what could happen, but you are in that situation, and I still think it … it's better than cancer … I was given a leaflet that listed what might happen and two of them did*' (P6)
		'*I was conscious that I could be restricted in my kind of movement and strength in my shoulders because the surgery involved … its muscles contract in an unusual way and I suppose it took me a while to adjust to that*' (P4)
		'*I had been diagnosed with osteoporosis before my first diagnosis … I was very worried at the time I was going onto the Arimidex about what that would to my bone health*' (P7)
2. Access to support services in survivorship	Positive experience	'*You met a lot of other people [at a support group] who were able to tell you things that they found useful or didn't find useful … So that interaction with other people who had been in the same position I thought was very beneficial*' (P6)
	Negative experience	'*I felt where everything has fallen down for me is the follow-up care … I've had to do this all myself, and I don't think that's right … it was like being pushed into sea from shore on a boat with no oars … like what now? What do I do?*' (P3)
		'*… if I had needed it [support], I didn't have anywhere to access it*' (P4)
	Support not accessed	'*Well, there was a support group there … I didn't think I needed it … I suppose if my cancer had been farther advanced, I probably would have needed it more*' (P5)
		'*I didn't avail of any of the psychological services afterwards [failed reconstruction] … I did have advice obviously from the nurse specialists … so I would have dropped in to see them a couple of times … but I haven't engaged much with the services this time around as I feel there's not much they can do for me*' (P7)

treatment of chemotherapy induced Achilles tendonitis and plantar fasciitis. They spoke of having to source their '*own physio … own MRIs … [and] own X-rays …*' to investigate a co-morbidity of her cancer treatment. This participant felt that they '*… should have been able to go back in where* [they] *had* [their] *treatment and have somebody take you seriously.*'

Three two themes formed around this core concept and will be reported individually in sub-sections as the following: (1) health and rehabilitation post-treatment and (2) access to support services.

Health and rehabilitation post-treatment

Participants discussed what rehabilitation meant to them and all participants discussed a multi-faceted and holistic rehabilitation process. This included support groups,

information and both physical and psychological well-being. For the survivors who were interviewed, an important aspect of rehabilitation appeared to be returning to some form of normality:

> I suppose the word rehabilitation to me is about getting from a place where something has stopped you doing what you would normally do to get back to where you want to be, or as close to that as possible. So, in terms of my journey, it's about getting back to … my life in the best way that I can (P8]

> I suppose it's going back into a normal life … you're in a sort of bubble but it's quite a secure bubble … So, I suppose rehabilitation is what life is going to be from now on (P6]

This theme generated sub-themes, which will be explored in turn, including mental and physical health, control and potential co-morbidities.

Health in survivorship

All participants discussed both physical and mental wellbeing in survivorship and reflected on the role of rehabilitation in rebuilding their health:

> Rehabilitation means I'm good enough to try to increase my stamina and do more exercise … because … I don't seem to have the stamina to do things. I think I can do them and then I'm absolutely wiped out (P2]

Another participant highlighted the importance of taking control of their health in survivorship:

> It [the cancer diagnosis] made me very conscious of the control I had of my health after the treatment had finished … I was very conscious of what I could do to make sure I stayed healthy (P6)

All participants discussed their exercise in survivorship, with differing experiences of returning to exercise in survivorship. One participant explained:

> Oh it [my exercise routine] is still the same, … I try and get out, I'm back working, I try and get out for a walk every day, I'm not quite up to my 5K but I'm getting there … slowly, slowly, steady, steady wins the race. I do my Pilates online (P3)

Another highlighted the different experiences they had between physical and psychological rehabilitation:

> I was lucky that physically my rehabilitation was easy … but I suppose psychologically that's the area that is harder … it's a more complicated rehabilitation because it's about, you know, how you think and behave and how you get back into your life, and you know, your attitudes to some things change … (P4)

Some participants discussed prioritising themselves more, spending less time worrying about the 'mundane', and employing mindfulness and meditation techniques to help manage stress. A breast cancer diagnosis and subsequent treatment appeared to put life into perspective for the survivors, whether it was actively looking after their health through eating well and exercising more or managing stress within their lives:

> I mean the most important thing for me in terms of staying well is to avoid stress, try not to let myself get stressed out. I try not to let myself get burnt out (P7)

As discussed in a later theme, not all participants felt they had access to adequate support during survivorship. One participant recognised this as having a negative impact on her mental wellbeing during survivorship:

> That's [psychological support] quite important actually and maybe this is something that I missed a bit … I felt that I was on my own … (P1)

Desire for control

Survivors stated that they wanted to actively be in control over their health during their survivorship with some explaining it was something they felt they had taken for granted before their diagnosis:

> 'I've always wanted to be healthy … everybody wants to be healthy. But when you get the [cancer] diagnosis, you do realise, you realise that this isn't in your control anymore (P6, view of health after diagnosis)

> But it [a breast cancer diagnosis] made me very conscious of the control I had over my health after the treatment had finished. And I was very aware that both exercise and diet were going to have a lot to do with the future for me (P6, view of health as a survivor)

Some participants explained they were determined to maximise their rehabilitation, taking all measures they felt they could:

> I am determined to get back, but I mean whether I ever get back to what I was, I don't know (P2)

> I am back in Pilates, and I've changed from mat classes to reformer classes because its more on the muscle, its's more intense … I still don't drink and I don't smoke and we are very careful about the majority of foods (P3)

> Diet is critical really, I think, exercise is critical, maintaining a healthy weight and a maintaining a healthy mindset … (P7)

However, that sense of control was not experienced by all survivors, with one participant describing survivorship and recovery as a 'lottery', illustrating a sense of a lack of control:

> I knew people who had died from breast cancer, and I knew people who had recovered well, and it just seemed like a lottery in some ways … I think it [a second diagnosis] just had reinforced for me that it is kind of a lottery once you have cancer … (P7)

Awareness of potential co-morbidities

Each survivor had a different experience of chronic conditions following their cancer treatment, including plantar fasciitis and tendonitis, tenderness of the breast, infertility, restriction of physical movement, pneumonitis and nose bleeds. An awareness of potential co-morbidities arose when discussing the diagnosis and early treatment journey with participants. The source of this knowledge was not always discussed, but some participants explained they'd received leaflets from their medical team. One participant explained:

> I'd read about what could happen, but you are in that situation, and I still think it … it's better than cancer … I was given a leaflet that listed what might happen and two of them did (P6)

Two survivors identified the potential risk to their cardiovascular health because of the treatment that they had:

> I knew that there might be side effects in relation to that [radiation treatment], so I'd be mindful of that, I've had my heart checked a couple of times … (P7)

> I asked 'why?' [they were receiving an echocardiograph]. And I was told it was because of the treatment, but I said 'why? … Like what's in the treatment that you're doing this [echocardiograph]?' and then eventually I wangled the information out of them (P3)

Although these two survivors recognised the risk to their cardiovascular health and employed measures to continue to look after it, other survivors did not appear to be aware of this risk. This included survivors who were receiving cardiovascular tests as part of their aftercare. One survivor who had received 3-monthly scheduled echocardiograms following their treatment could not recall why she was receiving aftercare specific to her cardiovascular health:

> Is that [the risk of CVD] why I had a … an echocardiogram? … They didn't explain that really, I don't think. Mind you, it's all a bit of a blur to be honest (P2)

When introduced to this risk, one survivor expressed an interest to learn more about it and its association with cancer treatment:

> What is the link [between CVD and breast cancer]? What is the mechanism of that? (P1)

Access to support services in survivorship

Survivors reported one of three experiences when accessing support during their survivorship. Positive experiences of support and support services that provided tools to aid them during their survivorship; negative experiences of accessing support that left survivors feeling alone in their survivorship journey; or survivors felt that they did not need support in their survivorship journey.

Positive experience

Survivors discussed accessing support through several different pathways, including psycho-oncology services provided by their hospital, Facebook Support Groups, independent charities such as Penny Brohn and Macmillan, and Health Service Executive (Ireland) programs curated specifically for breast cancer survivors. Survivors reported the benefits of support and engaging with women who had been through similar journeys:

> I can't sing their [a UK based charity] praises enough. I mean, I know, I'm probably

> slightly biased, [due to family links to the charity] but … they've been phenomenal and invaluable (P8, positive experience of accessing support]

Survivors who had positive experiences of support recognised the disparities of geographical location and access to support that other survivors may face. This was something which is covered in the negative experience sub-theme:

> I'm very aware that had I lived somewhere else, I wouldn't have had access to the support I had, and my, my outcomes could have been different, you know (P8)

Negative experience

Some survivors felt alone during their survivorship journey, feeling they had no means to access support after their treatment had finished. These survivors either accessed support through independent charities or online groups on platforms such as Facebook.

> … the majority of support I've found, and I know it's an awful thing to say, but it's actually been support groups on Facebook (P3, negative experience of success to support)

One survivor explained that HCPs '*have to hear what's being said*' when it comes to rehabilitation and survivors seeking support for both physical and psychological health. This survivor described feeling that she wasn't being listened to by her care team during her survivor journey, and felt she had to seek follow-up care alone. Locality, particularly amongst the survivors based in Ireland, was discussed in relation to access to support services. The concept of access to support services in rural versus urban areas emerged among all survivors who were in the Republic of Ireland (62.5%). Several survivors who lived in rural areas had to travel to their cancer treatment, with one survivor travelling 300 km to receive radiotherapy weekly. By contrast, a survivor who lived the urban area of Dublin travelled 3 km to receive the same treatment. This had a clear impact on how and if they accessed support services during their survivorship:

> … [I'd be told] well you know you've got to go to your local area [for support]. Well, I'm like there's no one in my area (P3, County Cork, ROI)

> So, I availed of a local support group rather than one near the hospital … the hospital was in Dublin, so it was a bit of a distance (P4, County Laois, ROI)

> … you just built up on the community of people yourself, it was just our own little network, there was nothing formal after that and that's probably to do with, you know, the way we're located (P6, County Donegal, ROI)

For context, the Irish Cancer Society provided a list of cancer support services in the four provinces (26 counties) of the Republic of Ireland (ROI). Figure 2 illustrates the disparity in cancer support across the ROI; seven counties have no cancer support services, whereas one county has seven cancer support services. The map highlights how services are limited in rural areas of the country, compared to those in urban areas as reflected by participants of this study.

Support not accessed

Some survivors did not access support during their survivorship for one of two reasons: they felt that they did not think they needed it, or they felt that the support services could not do anything for them in their survivorship journey. One survivor explained that they 'just get on with it' and used their family as a support system. Another added:

> I know there are places that you can ring if you need to talk to them. And there are groups there to help you through it but I … I found that I didn't need that support (P5)

Another felt that they didn't want to play the 'victim' role of a cancer survivor and therefore did not access support groups. This survivor reported a feeling of guilt after receiving her second diagnosis. They explained how they felt that their 'drinking to excess' may have contributed to the recurrence of cancer, as a result of the 'one in eight' health promotion campaign in the Republic of Ireland that relates one in eight breast cancers to alcohol consumption. Therefore, they felt that seeking treatment for alcohol abuse was a 'more important journey' than seeking psychological support specifically for their cancer: '*I actually sought treatment for alcohol abuse subsequently the following year and I'm now sober, I don't drink at all. And I kind of felt that that shifted things completely for me*'. This participant also explained how the support accessed in this group helped with their cancer survivorship journey:

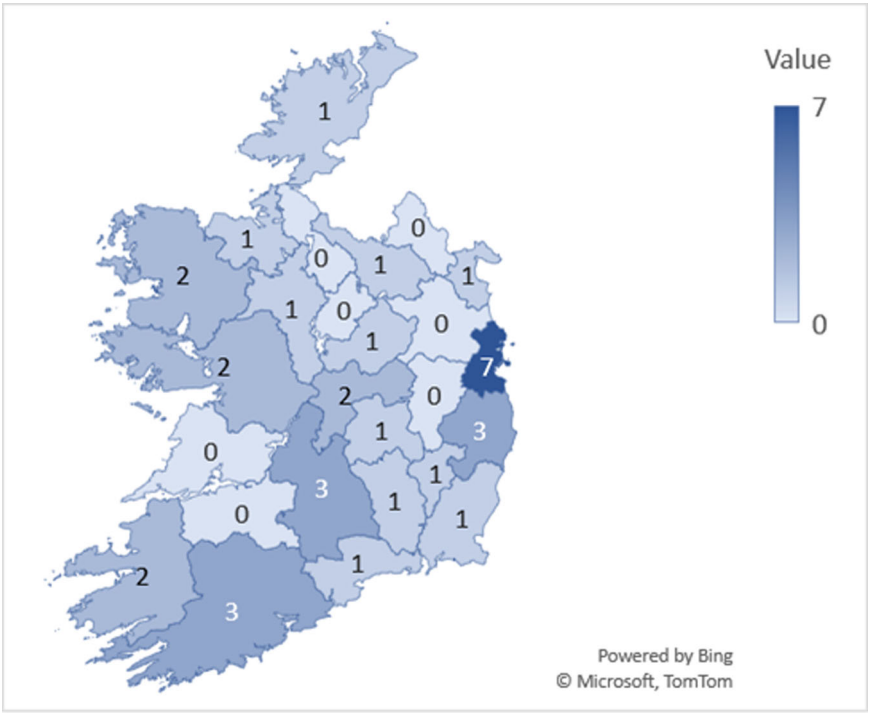

FIGURE 2 Location of cancer support services

> I suppose in terms of the breast cancer, I would deal with it in terms of my recovery programme, really it would be part of that in terms of a 12-step programme. You know, things that happen in life (P7)

This experience further reiterates the uniqueness of each cancer survivors' journey and the varied range of support systems that are accessed and required.

DISCUSSION

The present study aimed to investigate health during breast cancer survivorship and survivors' access to and awareness of rehabilitation support in survivorship. It emerged that, although survivorship is a unique experience and the pathways that each survivor takes may differ, a holistic approach to health appeared to be a key aspect of survivorship, including diet, exercise and stress reduction. Unanimously, access to rehabilitation support was considered a to be a vital component of survivorship care; however, access to support differed and was lacking for many.

Health was considered a principal aspect of survivorship for every participant. Breast cancer survivors expressed a lack of control over their health after they received their diagnosis, which, for most, resulted in them prioritising areas they could control in survivorship such as diet, exercise and stress reduction. Although all participants discussed their diet prior to diagnosis, suggesting they understood it to be important to general good health, only one raised diet in relation to their survivorship, perhaps highlighting a gap in the knowledge of nutrition in survivorship. This is pertinent because females undergoing chemotherapy have been reported to be at a high risk of malnutrition[18] and breast cancer patients have been reported to experience changes in weight including weight gain.[19] Our findings are perhaps reflective of a lack of patient education regarding nutrition in cancer recovery. A 2020 study reported that only 15% of healthcare organisations, cancer charities and support groups provided nutrition guidance for cancer patients, whereas just 9.3% provided guidance for cancer survivors.[20] This is echoed by the findings of de Kruif *et al.*[19] who reported that breast cancer patients undergoing chemotherapy experienced little dietary support from HCPs during treatment despite this treatment often negatively impacting dietary intake, with those reporting poorer intake experiencing more fatigue and perceiving less opportunities to be physically active. Research shows that cancer diagnosis alone is not sufficient to bring about changes to dietary intake, therefore highlighting the role of intervention to facilitate change.[21] Taken together, this evidence suggests there is a lack of education regarding nutritional guidance for cancer patients and survivors. This is clearly an area where dietitians could make a significant contribution to improving patient outcomes and future work should explore the role of the dietician in cancer survivorship.

There also appeared to be a lack of understanding regarding longer term co-morbidities of cancer-treatment. Only two participants raised the risk of

CVD with treatment despite this being a primary cause of death among cancer survivors.[22] It appears that more must be done to provide survivors with an awareness of this risk. Clinicians treating breast cancer must be comfortable with addressing the longer-term impacts of treatment, including cardiotoxicity, so that survivors can be educated toward appropriate health-behaviour change and screening.[12] This might include dietary guidance as previously explored within this work. Within our study, some participants expressed a desire to understand all possible co-morbidities of treatment, whereas others felt that discussing the 'mights' may have contributed to feelings of stress and being overwhelmed. Some participants found that receiving information leaflets was helpful because they could take the information in at their own pace, whilst others found the process to be a 'bit of a blur'. This reaffirms the need for survivors to have access to rehabilitation support that individualises their needs and provides a care plan accordingly, as well as identifying and educating survivors about co-morbidities that they may not be aware of.

Psychological support in survivorship was considered important by participants within this study. Survivors who had access to support (e.g., psycho-oncology services or counselling) reported that they continued to use the tools that these services had provided them with throughout their survivorship journey. One participant explained how strategies learnt during their alcohol-support group helped in navigating their cancer-recovery, highlighting that support looks different for all survivors. A recent consensus view from Macmillian, the Royal College of Anaesthetists and the National Institute for Health Research reported that, despite the area being in its infancy, psychological intervention shows promising psychosocial outcomes including anxiety and depression albeit in the perioperative and not the survivorship period.[23] Many of the survivors in our research felt that psychological rehabilitation was more challenging than physical rehabilitation, and also reported feeling unsupported during their survivorship journey. This resonates with findings of similar literature.[11,24] These findings suggest that there is an urgent need to progress the support that patients and survivors have access to in the period from diagnosis, through treatment, and into survivorship.

There were mixed experiences regarding access to support in survivorship. Notably, survivors located in Ireland raised disparities in accessing support services in rural and urban locations. The Irish Cancer Society provides a list of support services available to allow for comparison. Urban areas, such as Dublin, have three or more support centres listed, whereas more rural counties, such as Donegal, only have one support centre listed. This had a clear impact on how and whether survivors accessed support services. This is in agreement with findings by Haigh *et al.*[25] who reported the physical isolation rural cancer survivors may experience in comparison to more urban counterparts. In addition to physical barriers to support, one survivor in this study felt that she was not listened to when she raised concerns during her survivorship. This survivor described her transition from 'patient' to 'survivor' as being pushed into sea on a boat with no oars. This experience has been noted in the literature, with Meade *et al.*[11] reporting that some breast cancer survivors feel 'dismissed' by HCPs when they raise concerns. Cleary, the transition from active treatment to survivorship care needs to be considered as continuous as the transition is from diagnosis to active treatment for patients.

Participants stated that they would like access to a rehabilitation or support centre that focussed on the 'whole' person. Despite this, many participants had no awareness of rehabilitation or cancer support centres available to them. The Independent Cancer Taskforce[26] recommended a national review of the cancer rehabilitation workforce and promoted the role of allied health professionals in multi-disciplinary teams, as a result of inconsistencies in access across the cancer pathway. Despite advances in the field, clearly more must be carried out to improve access to rehabilitation and support in survivorship; however, it will also be important to do this in a streamlined and efficient manner drawing upon proven successful models. The British Association for Cardiovascular Prevention & Rehabilitation (BACPR) provides specific standards and core components for cardiac rehabilitation. The core components are long-term strategies for disease management, promoting lifestyle and risk factor management, psychological health, supporting health behaviour change and education, addressing medical risk management, and encouraging audit and evaluation of practice.[27] These core components are clearly transferable to a cancer rehabilitation model and embedded within them is the importance of a multidisciplinary team with respect to providing patient care, including dietitians. This is very much in line with the components of the Move More service.[27] It may be that, given the increased survival rates from cancer and the potential for latent cardiotoxic effects, cardiac rehabilitation services are required to accommodate cancer survivors in future. Current investigations provide an argument that such cardiac rehabilitation models are feasible and can improve cardiorespiratory fitness and QoL in cancer survivors.[28] More recently Zvinovski *et al.*[29] have shown this model to be feasible in breast cancer patients ($n = 18$). In a 14-week cardiac rehabilitation intervention, there were significant improvements in patient reported PA, fatigue and QoL. This occurred without any significant improvement in CVD risk factors; however, this is likely a result of overall adherence to the study being too low to bring about physiological improvements (60%). This is in agreement with findings by Turner *et al.*[30] who reported that only 57% of interventions had targets that meet government PA guidelines, with only

62% of those reporting adherence of > 75%. Despite this, however, improvements in aerobic fitness were seen at 2, 3 and 6 months. These findings suggest that early implementation of a rehabilitation program could be considered for cancer patients and survivors.

The limitations of the present study are acknowledged. Although the study employed a relatively small sample, the methods employed to ensure rigor and trustworthiness of the data enhance the credibility of findings.

CONCLUSIONS

Our findings in conjunction with the extant literature highlight that rehabilitation and support services need to be more readily available for to cancer survivors. Furthermore, there needs to be education regarding the increased risk of CVD with cancer treatment, as well as risk-reducing strategies to manage this. Cardiac rehabilitation models may be a feasible means of delivering cardio-oncology care to cancer survivors. This could provide a holistic approach to survivorship care and a seamless transition from 'patient' to 'survivor', giving the lifelong support that cancer survivors both want and need.

AUTHOR CONTRIBUTIONS

Elizabeth Deery: Methodology, Analysis, Writing – original draft, Visualisation, Administration, Supervision. **Katie Johnston**: Conceptualisation, Investigation, Analysis, Writing original draft. **Thomas Butler**: Conceptualisation, Methodology, Writing – review & editing, Visualisation, Supervision.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY

The data that support the findings of this study are available from the corresponding author upon reasonable request.

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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PEER REVIEW

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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