Nutritional assessment and dietetic resource for children and young people with cancer in the United Kingdom

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Abstract

Background: Both under- and overnutrition may have adverse impact on outcome of cancer in children and teenagers/young adults (CTYA). Previous studies confirm that screening for nutritional risk and detection of nutritional abnormality is inconsistently undertaken in practice.

Methods: We undertook a survey of dietetic resource and nutritional assessment in CTYA principal treatment centres (PTC) in the United Kingdom. Responses were received from 95% children’s and 69% TYA PTC.

Results: Only 13/18 (72%) children’s PTC, and one of 11 (9%) TYA PTC, met national standards for dietetic resource; one of 18 (6%) paediatric and six of 11 (54%) TYA PTC had no such resource. While resources were greater in larger paediatric PTC, who were also most likely to undertake stem cell transplantation, resources in TYA PTC were too low to assess relationship to centre size. Most centres focused resources on inpatient care and <50% considered staffing adequate; 82% used nutritional screening tools but without consistency in the tool used. Weight and height were the principal method for assessment, but with inconsistency in the frequency of measurement and use in different clinical settings. Measures derived from weight and height, including body mass index (BMI), were inconsistently utilised. The use of arm anthropometry was rare despite evidence that use increases recognition of undernutrition. Detailed nutritional assessment was infrequently attempted.

Conclusion: Barriers to adequate nutritional assessment and treatment for all patients include resource limitations (particularly TYA), training for staff, and uncertainty about detailed assessment of nutritional status. There is a need to harmonise screening and assessment of nutritional status in CTYA with cancer.

Abbreviations: BMI, body mass index; CTYA, children and teenagers/young adults; HCA, health care assistants; IQR, interquartile range; MNA, Mini Nutrition Assessment; MUAC, mid upper-arm circumference; MUST, Malnutrition Universal Screening Tool; NRS-PC, Nutrition Risk Screening for Pediatric Cancer; PG-SGA, Patient-Generated Subjective Global Assessment for nutrition; PNRS, Pediatric Nutrition Risk Score; PTC, principal treatment centres; PYMS, Paediatric Yorkhill Malnutrition Score; SCAN, nutrition Screening tool for childhood Cancer; SCT, stem cell transplantation; STAMP, screening tool for the assessment of malnutrition in paediatrics; TSFT, triceps skinfold thickness; TYA, teenagers/young adult; WTE, whole-time equivalents.
1 | INTRODUCTION

Five-year survival rates for children and teenagers and young adults (CTYA) with cancer in developed countries are now over 80%, although considerable variation remains in survival by diagnosis. Alongside sequential improvement in the efficacy of treatment has been improved supportive care, of which nutritional support is a major component.

Nutritional status can be defined as the extent to which the demands for energy and nutrients are satisfied by dietary supply. Body shape, size/growth and composition meet the body’s needs and serve as the most readily accessible markers of nutritional state. Other markers include the quantity and quality of the diet, together with physiological and metabolic markers of function such as physical function and micronutrient status. No single measure defines nutritional state and measurement of body size, and composition remains the most frequent approach.

Nutrition screening tools are brief risk assessments carried out by health care professionals to identify those who are likely to be malnourished or at risk of becoming malnourished, warranting more detailed nutritional assessment and intervention. Some tools are designed for nutritional screening in hospitalised children in general and include STAMP (Screening Tool for the Assessment of Malnutrition in Paediatrics), PYMS (Paediatric Yorkhill Malnutrition Score), STRONG Kids, and PNRS (Pediatric Nutrition Risk Score), but the optimal choice is debated. More recently, screening tools have been promoted specifically for children with cancer, including SCAN (nutrition Screening tool for childhood Cancer) and NRS-PC (Nutrition Risk Screening for Pediatric Cancer), but experience of both is limited. More detailed tools offering a standard approach to nutritional assessment are also available, including the SGNA (Subjective Global Nutritional Assessment for children).

Screening tools for adult patients that may be used for older teenagers and young adults include MUST (Malnutrition Universal Screening Tool) and MNA (Mini Nutrition Assessment), which are generic and PG-SGA (Patient-Generated Subjective Global Assessment for nutrition), which is cancer specific. Previous studies both from the United Kingdom (UK) and elsewhere have highlighted the lack of consistently applied guidance to improve nutritional screening, assessment, and care in CTYA with cancer.

A previous survey of clinical practice in children’s cancer care in the UK highlighted inconsistencies both in assessment of nutritional status and in approaches to intervention. The unresolved need for a standard approach stimulated interest in a further survey to identify how far change in clinical practice had evolved in both children and TYA, and to inform the development of guidance to harmonise assessment and management of nutritional care for the future.

2 | METHODS

2.1 | Study design

The content of the previously published UK survey was amended or supplemented by consensus discussion based on awareness of current practice. It was agreed that the survey should re-address only the measurement of nutritional status and that, to capture a consensus of local practice rather than individual opinion, only one representative response would be sought from each participating centre.

The survey was formatted for electronic completion using Qualtrics on-line survey software. Responses were structured to allow the frequency of observations to be reported as follows: Usually (applies to >70% patients); Sometimes (30%–70% patients); Rarely (<30% patients); Never; and Don’t know.

2.2 | Setting

The survey was distributed to the lead clinician, a senior nurse and a dietician at all Children’s and Teenage and Young Adult (TYA) principal treatment centres (PTC) within the United Kingdom.

2.3 | Data collection

The survey requested numbers of new patients registered each year, age range of patients treated and whether the centre undertook stem cell transplantation (SCT); allogeneic SCT was selected as a readily identifiable proxy indicator of the complexity of treatment undertaken in view of the known high nutritional needs of such patients.

Dietetic resources were estimated by the number of dietetic positions, measured as whole-time equivalents (WTE) designated for CTYA cancer care, and the extent to which routine dietetic care was offered in inpatient, outpatient/day care and long-term follow-up settings. Respondents were also asked to indicate whether they thought their dietetic resource was adequate for the size of the clinical service.

Information was sought about the use of local policies and the provision of training regarding the measurement and recording of weight and height; the use of alternative methods in addition to/instead of weight and height; the use of nutrition screening tools; and the detail of extended nutritional assessment, including measurement of micronutrients, dietary intake and energy expenditure. Free-text responses were invited to clarify reasons for not utilising any of these methods and to better understand barriers to their implementation; this included a request for information about training given to staff.
2.4 Pilot experience

A preliminary version of the survey was shared with a small number of individuals in seven centres for pilot completion and comment: the feedback received influenced the clarity, content and length of the final version.

2.5 Analysis

Responses were analysed using descriptive statistics, and comparisons were made with the previous UK survey. Data distributions were analysed as medians with interquartile range (IQR). The relevant denominator and percentage are given for individual measures as all centres did not respond to all questions.

2.6 Ethical approval and consent

Guidance issued by the NHS Health Research Authority confirms that formal ethical review is not required for service evaluation. Participants were invited to contribute to the survey and gave their consent on the basis that individual responses were anonymised and data would be handled in accordance with UK data protection regulations.

3 RESULTS

3.1 Characteristics of participating centres

Twenty-eight responses were received providing information about 19 paediatric and 11 TYA PTC (centres), representing 95% of all paediatric and 69% of all TYA PTC in the United Kingdom; two responses provided information about paediatric and TYA services provided on the same site. Responses were completed by 23 dieticians, four nurses and five doctors. In six cases, responses were submitted jointly by two or more professionals, but it was otherwise unclear how much multiprofessional collaboration took place prior to submission.

The age distribution in each centre varied: one gave the upper age limit for new patient referrals as 13 years, seven as 16 years and eight as 18 years. All others described an upper age limit of 25 years, implying either continuity with children’s services or status as a TYA unit only.

Twenty-one (70%) of the centres undertook allogeneic SCT.

3.2 Dietetic resource

The quantity of designated dietetic resource (including dietetic assistants, where employed) was reported by 29 centres (18 paediatric, 11 TYA) and ranged from 0 to 4.17 WTE. Median resource was 1.35 WTE (IQR 1.7) in paediatric versus 0.1 WTE (IQR 0.3) in TYA centres. Overall, 13/18 (72%) paediatric centres had at least 1.0 WTE and only one had no designated resource. Six of 11 TYA centres (54%) had no designated resource, although three of these reported access to dietetic resources from adult cancer services. Only one of 11 (9%) TYA centres had resource ≥0.8 WTE.

It was difficult to clarify the relationship between available resource (WTE) and size of centre (defined as new patient registrations/year) or complexity of care (defined as provision of allogeneic SCT). Although paediatric centres registering ≥100 new patients/year had greater dietetic resource (median 2.30 WTE [IQR 1.78] vs. 0.60 WTE [IQR 1.10] for those with <100 new patients/year), these centres were also those most likely to undertake SCT. The median resource for those undertaking SCT was 1.83 WTE (IQR 1.32) versus 0.75 WTE (IQR 0.90) for those who did not. Ten (of 11, 91%) TYA centres undertook allogeneic SCT, but designated dietetic resource levels were so low that it was not possible to determine the relationship to centre size and complexity.

When asked which areas of care the resources were available to cover, 21/29 (72%) centres indicated dietetic cover for inpatient care but fewer indicated the same for outpatient (11/29, 38%) and day-care (13/29, 45%). Only two of 24 (7%) centres considered they had resource to cover long-term follow-up care. In response to the question ‘do you think the dietetic service is adequately staffed for inpatient care?’, 13/29 (45%) responded positively. Only four of 29 (14%) indicated an adequate resource for outpatient and day-care work. Free-text comments highlighted the challenges of working part time or as a single-handed practitioner; the impact of increasingly complex treatments; the disproportionate demands of patients undergoing SCT; and the inability to adequately follow up patients on supplementary enteral feeding in clinic or at home.

3.3 Established local policies

The survey asked whether local policies existed for different elements of assessment. Twenty-six of 29 (90%) indicated a policy existed for the measurement and recording of weight and height, 20/28(73%) for nutritional screening, but only nine of 27(33%) for formal nutritional assessment (defined as an assessment involving functional, nutritional and metabolic variables).

3.4 Screening tools

Twenty-three of 29 responses (79%) confirmed that an inpatient nutritional screening tool was in use at their centre. These included STAMP/modified STAMP (n = 6), PYMS (6) and STRONGKids (2) in children’s centres and MUST for patients over 18 years in TYA units (n = 5). Four centres used their own tool. None used PNRS, SCAN, MNA or PG-SGA.

Policies in most centres (18/24, 81%) suggested that a screening tool should be used in inpatients at diagnosis and weekly thereafter, but two of 24 (8%) only specified use at diagnosis and two of 24 (8%) reported more frequent use for those with a low initial score, and in infants. Free-text comments referred to a lack of consistency in ensuring that screening was carried out and recorded. Reasons for not using
a screening tool were given by five centres and included insufficient staff time \((n = 4)\), unsure which tool to use \((1)\) and not being part of current practice \((1)\).

Only four of 29 \((14\%)\) centres reported the use of screening tools in outpatient or daycare settings; the principal reason for not doing so was given as lack of staff time. Reservations were also voiced about the validity of screening tools and difficulty in incorporating their use into electronic patient records.

### 3.5 Weight and height

Table 1 records data obtained about the frequency with which weight and height were recorded and in what setting. Weight was more frequently recorded than height in all settings and was recorded usually \( (> 70\% \text{ of patients})\) in 23/27 \((85\%)\) of centres at diagnosis, in 24/27 \((88\%)\) at each inpatient admission and in 20/27 \((74\%)\) at clinic visits. Height was usually recorded at diagnosis in 20/27 \((71\%)\) centres, but was thereafter measured less frequently—nine of 28 \((32\%)\) at inpatient admissions and 11/28 \((39\%)\) at clinic visits. Free-text comments recorded concern about the accuracy with which height was recorded and noted that height was measured less frequently in TYA settings but without documenting evidence that growth was complete.

Calculations derived from weight and height measurements were variably implemented: plotting height and weight on centile chart 14/28 \((50\%)\) centres; body mass index \((\text{BMI})\) 17/28 \((61\%)\); \% weight/height seven of 27 \((26\%)\); weight loss since diagnosis 10/27 \((37\%)\); and weight standard deviation scores \((\text{SDS})\) six of 26 \((23\%)\).

Twenty-four centres responded to a question about alternative approaches if clinical circumstances prevented normal weight or height measurement. For weight (multiple answers were possible), the use of self-reported or estimated weight was reported by five of 24 \((21\%)\) centres; hoist, sitting scales or weight with parent by six \((25\%)\); and mid upper-arm circumference \((\text{MUAC})\) was used by 11 \((46\%)\). For height, responses included use of a supine mat \((1/24, \ 4\%)\), demispan \((3/24, \ 12\%)\) and ulnar length \((6/24, \ 25\%)\).

### 3.6 Arm anthropometry and other measures of body composition

Table 2 records data obtained about the frequency with which arm anthropometry and other measures of body composition were undertaken. No centre usually recorded MUAC, and 25/28 \((89\%)\) reported its use rarely or never.

Triceps skinfold thickness \((\text{TSFT})\), dynamometry and bioelectrical impedance were recorded as rarely or never used in 93\% \((26/28)\), 86\% \((24/28)\) and 93\% \((26/28)\) of centres, respectively.

Free-text comments suggested that lack of staff training/confidence in undertaking these measurements were the principal reasons for not undertaking MUAC, while lack of equipment and staff training were cited as reasons for not undertaking TSFT, dynamometry and bioelectrical impedance.
TABLE 2  Frequency of measurement of arm anthropometry and other measures of body composition reported by treatment centres

| Proportion of patients | Usually > 70% patients | Sometimes 30%–70% patients | Rarely <30% patients | Never | Don’t know | Total responses |
|------------------------|------------------------|--------------------------|---------------------|-------|------------|----------------|
| Mid upper-arm circumference (MUAC) | 0 | 1 | 20 | 5 | 2 | 28 |
| Triceps skinfold thickness (TSFT) | 0 | 0 | 2 | 24 | 2 | 28 |
| Hand grip strength (dynamometry) | 0 | 2 | 4 | 20 | 2 | 28 |
| Bioelectrical impedance | 0 | 0 | 2 | 24 | 2 | 28 |

TABLE 3  Frequency of measurement of food intake reported by treatment centres

| Proportion of patients | Usually > 70% patients | Sometimes 30%–70% patients | Rarely <30% patients | Never | Don’t know | Total responses |
|------------------------|------------------------|--------------------------|---------------------|-------|------------|----------------|
| Diet history completed by dietician | 16 | 7 | 4 | 0 | 1 | 28 |
| Nursing food record chart | 17 | 6 | 3 | 0 | 2 | 28 |
| Food diary | 5 | 5 | 17 | 1 | 0 | 28 |
| 24 Dietary recall | 13 | 6 | 2 | 3 | 3 | 27 |
| Food frequency questionnaire | 1 | 2 | 10 | 12 | 3 | 28 |
| Weighed food diary | 1 | 0 | 6 | 18 | 3 | 28 |

3.7  | Laboratory-based assessment

Elements considered integral to nutritional assessment varied. In terms of laboratory investigations, albumin was regarded as being usually/sometimes relevant in 19/26 (73%) centres, while prealbumin (21%), transferrin (29%) and retinol binding protein (8%) were much less often considered. Twenty of 26 centres (71%) confirmed that they sometimes measured micronutrients but that this was infrequently done routinely except in four (15%) centres who had policies for measuring vitamin D. Other comments noted that micronutrient measurement was undertaken only in undernourished patients and in those on supplementary enteral or parental feeding. Overall, there was little clarity about why or when micronutrient measurement should be undertaken.

3.8  | Dietary intake

Table 3 records data obtained about the frequency with which dietary intake was recorded. Dietary history and nursing observations of food intake were the most frequently used forms of assessment (used usually or sometimes) in 23/28 (82%) centres, followed by 24-hour dietary recall (19/27, 70%). Other techniques were used in varying but lower frequencies. Food frequency questionnaires and weighed food diary were rarely or never used (22/28 [79%] and 24/28 [86%], respectively).

Twenty-five (89%) responses indicated that energy requirements were calculated in their centres but only two of 28 (7%) reported calculation of energy expenditure. Lack of access to equipment and lack of staff training were cited as the most frequent reasons for lack of use, and free-text comments revealed uncertainty about its utility.

3.9  | Staff roles and training

Measurements of weight and height were undertaken by all staff groups, but most frequently obtained by nurses and health care assistants (HCA); plotting of centile charts was more frequently undertaken by doctors and dieticians. Nutrition screening tools were almost all completed by nurses and HCA, less frequently by dieticians and never by doctors.

Training for all staff groups was said to be available for measuring weight and height (in 21/28 [75%] of centres); completing centile charts 13/28 (46%); administering nutritional screening tools 18/28 (66%); but only provided for other methods, including arm anthropometry, in 11/28 (40%).

3.10  | Key messages from previous UK survey (Selwood et al.)

Table 4 provides a summary of major differences and similarities between this survey and the previous UK survey.

4  | DISCUSSION

Malnutrition in patients with cancer may manifest as undernutrition, but more recent experience has highlighted the occurrence and significance of both overnutrition (obesity) and in the sarcopenic changes in body composition seen following treatment. Increasing data suggest that both under- and overnutrition may have an adverse impact on outcome. Most are studies in leukaemia, but data are accru-
TABLE 4 Differences and similarities between the previous survey (2010)\textsuperscript{20} and this survey

| Differences                                                                 | Similarities                                                                 |
|----------------------------------------------------------------------------|------------------------------------------------------------------------------|
| **Setting**                                                                |                                                                              |
| Only paediatric oncology centres were approached in 2010 survey             | High response rate                                                           |
| **Data collection**                                                        |                                                                              |
| Majority of survey returns were submitted by nurses rather than dieticians |                                                                              |
| in 2010 survey                                                             |                                                                              |
| **Content**                                                                |                                                                              |
| 2010 Survey also included a request for information about nutritional      |                                                                              |
| intervention; this was specifically excluded in the current survey         |                                                                              |
| **Results**                                                                |                                                                              |
| Fewer dietetic resources reported by individual centres in 2010 survey      | No clear relationship between size of centre and resource availability        |
|                                                                              | Inconsistent practice in relation to measurement of weight and height and in |                                                                              |
|                                                                              | the use of measures derived from weight and height. Limited use of arm       |
|                                                                              | anthropometry                                                               |
| **Nutritional assessment**                                                 |                                                                              |
| Much more limited use of nutrition screening tools in 2010 survey           | No nationally agreed approach to the use of screening tools                   |
| Use of health care assistants to undertake measurement not reported in      |                                                                              |
| 2010 survey                                                                  |                                                                              |
| 2010 Survey publication provided a suggested list of diagnoses with high   | No nationally agreed approach to assessing risk                               |
| or low nutritional risk but without evidence base                           |                                                                              |
| 2010 Survey publication included a suggested minimum guideline for         | No nationally agreed approach to assessment. Limited use of arm anthropometry |
| nutritional status measures but without clear origin                        |                                                                              |

ing from children with solid tumours.\textsuperscript{34} The impact may be mediated by factors such as altered susceptibility to infection,\textsuperscript{35} but also by dosing inaccuracy and pharmacokinetic variables.\textsuperscript{36,37} There are also data implicating specific cellular mechanisms that may be influenced by nutritional state.\textsuperscript{38}

Long-term follow-up of survivors has identified the extent to which chronic health conditions may affect adult life. These include conditions such as cardiovascular disease, metabolic syndrome, type 2 diabetes, reduced peak bone mass, frailty and second malignancy, all of which may be promoted or exacerbated by nutrition-related problems that manifest during and after treatment.\textsuperscript{39–41}

Identification and incidence of nutritional abnormality is therefore of increasing importance, but depends on the method of assessment used. The results of our survey confirmed reliance on measures of weight and height, but identify an inconsistency with which even these measures are obtained, as well as limited use of alternative methods for estimating weight and height. The limited use of centile charts further constrains the utility of the height and weight data. Routine use of arm anthropometry was rarely applied despite evidence that its use increases the recorded incidence of undernutrition when compared with indices based on weight and height.\textsuperscript{1–3} Measures derived from height and weight, including BMI, were also inconsistently utilised, although interpretation of such data may be difficult as they fail to identify changes in body composition\textsuperscript{4–6} for which a number of methodologies exist, although dual-energy X-ray absorptiometry (DEXA) is the clinical gold standard.\textsuperscript{42} The limited use of dynamometry and bioelectrical impedance may reflect limited normative values for these methods of assessment in children as well as difficulties with access to equipment.

There is no universally accepted screening tool specifically designed for children with cancer to identify the risk of malnutrition. However, four non-disease-specific nutritional screening tools have been developed to identify both those at risk of undernutrition and those who are undernourished. All are widely used in hospitals,\textsuperscript{8–11} and are simple and easy to use. They are based, with some variations, on severity of disease, percentage weight loss, BMI and dietary intake. Nevertheless, a number of issues arise when these tools are applied to paediatric cancer patients: validity - none included more than a very small sample of children with cancer in their development; a child receiving cancer therapy might anyway be considered at high risk of undernutrition; and all tools screen for undernutrition, while overnutrition is overlooked. One screening tool (SCAN) has since been promoted specifically for children with cancer.\textsuperscript{14} It is based on a simple questionnaire that includes consideration of the type of cancer, likely intensity of treatment, history of gastrointestinal symptoms, report of poor oral intake, weight loss in the recent past, and the observation of physical features of undernutrition. Its sensitivity has been challenged\textsuperscript{15} and, like all the other tools, looks at nutritional risk: this is not equivalent to nutritional assessment, which involves a more detailed approach, including an examination of functional, nutritional and metabolic variables and is usually performed by a dietitian.

Different screening tools for adult patients are well described and may be used for older teenagers and young adults,\textsuperscript{17–19} but were
developed in much older adult populations; none have been formally validated in TYA.

Our survey showed a relatively high rate of use of screening tools but without a consistent choice. Several centres reported use of their own tools, or amendments to published tools, which may not have been formally validated, may be subject to measurement errors, and should represent only a temporary strategy for nutritional screening. No centre reported using one of the tools targeted at the child cancer population (SCAN and NRS-PC). An increase in the use of a screening tool was, however, one of the obvious changes in practice compared to the previous survey. This may have been stimulated both by increasing clinical awareness and by reference to nutritional support in service quality guidance for the United Kingdom. It was striking that screening tools were not being used in areas with limited dietetic support such as in outpatient and daycare settings despite these being circumstances where screening would be of value to guide onward referral and direct best use of specialist support. The lack of consistency found in the approach to nutrition screening is remarkable in paediatric oncology, where care is strongly protocol driven and the adequacy of supportive care has been demonstrated to contribute positively to outcome in terms of survival, morbidity and quality of life.

Previous national guidance had recommended a minimum workforce of 1.0 WTE dietitian for a paediatric PTC, and 0.8 WTE for a centre treating TYA. Our survey showed that this recommendation was met by only 72% of paediatric and 9% TYA centres, and likely itself to be inadequate. We were unable to identify published guidelines for workforce in similar settings and neither of the most recent national service specifications for CTYA cancer provide a target.

Staffing and workload (defined as new patients seen in a centre each year) appeared to show some relationship to size of centre but inadequate staffing resource, together with challenges in the training of staff other than dieticians to undertake screening and measurement, were frequently identified as major barriers to more consistent practice. The use of data routinely collected in electronic patient records may be a way forward and has been evaluated positively in the paediatric oncology setting. In most centres, resources available were targeted on inpatient care, with limited ability to support outpatient/daycare settings. The implementation of detailed nutritional assessment and support in long-term follow-up settings were all significantly constrained. The findings of this survey demonstrate a need to better harmonise the screening and assessment of nutritional challenges among CTYA with cancer.

A potential weakness of this study would arise if the proportion of CTYA referred to a PTC was unrepresentative. However, centralisation of care has been a long-standing feature of care in the United Kingdom. Data published in 2012 showed that 90% of children aged 0–14 years, diagnosed 2008–2010, were referred to a PTC. Services for TYA are also well established, although previous data show variation by age and by diagnosis. Sixty-two percent of those aged 15–18 years, diagnosed 2009–2010, were referred to a PTC compared with 42% of those aged 19–24 years and, for example, 87% of bone sarcoma patients aged 15–18 years were referred to a PTC compared with 21% with skin cancer (69% and 14% for those aged 19–24 years). Further work is needed to review available evidence to guide practice, define resource and measure the clinical impact of a consistent approach to nutrition assessment.

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CONFLICT OF INTEREST
The authors declare that there is no conflict of interest.

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

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