

SUPPLEMENT ABSTRACTS

BPOS Oral Presentations

Decision making in paediatric oncology: experiences and preferences of parents

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Presenting author: Eden Robertson

Background: Many families of children diagnosed with cancer are faced with difficult treatment decisions. They may be at risk of experiencing significant distress over their decisions.

Aims: We aimed to explore parents' treatment decision-making process, as well as any information needs and preferences.

Methods: We conducted semi-structured interviews with parents whose child had been diagnosed with cancer in the past 12 months. Interviews were audio-recorded, transcribed and analysed thematically. The study is ongoing; anticipated study close is December 17 (aim = 25 parents).

Results: To date, 17 parents (mean age of child at diagnosis = 7.4 y) have completed the interview (response rate = 35%). Early findings suggest parents find making treatment decisions "overwhelming" and "stressful." While most parents report a preference for shared decision-making with the child's clinician, they often feel as though they have no choice because of perceived lack of options or a lack of knowledge. Parents tend not to include their child in major decisions, however acknowledge the importance for children to be involved in day-to-day decisions. Many parents experience information overload, but also report a lack of understanding of information. Many parents also sought information online. Barriers to quality decision-making include feeling distressed and overwhelmed with information. Facilitators included a good relationship with their clinician and use of simple language.

Conclusions: Families require clearer information provided in multiple modalities, more guidance to engage in shared decision-making, and more emotional support throughout the decision process. These findings have contributed to the development of Delta—an online decision-aid supporting families deciding whether to enrol in a paediatric oncology clinical trial.

The holistic needs assessment in cancer care: identifying barriers and facilitators to implementation in the UK and Canada

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Background: Personalised information and support can be provided to cancer survivors using a structured approach. Assessment tools such as the Holistic Needs Assessment (HNA) in the UK and the Comprehensive Problem and Symptom Screening (COMPASS) in Canada have been recommended for use in practice. However, completion of the HNA/COMPASS is not widely embedded into practice and Clinical Nurse Specialists (CNSs) express concern about their ability to respond to issues raised by patients.

Aims: To investigate CNS's views on HNAs/COMPASS and identify barriers and facilitators to implementation.

Methods: This international on-line survey using a snowball technique recruited CNSs across the UK and one Canadian province (Manitoba) in 2017.

Results: A total of 306 CNSs in the UK and 162 in Canada completed the on-line survey. In the UK, HNAs were completed primarily prior to and immediately after treatment. In Canada, COMPASS was usually completed at every appointment. Participants expressed concerns that HNAs/COMPASS were becoming "tick-box exercises" which did not meet patients' needs. Barriers to completion were time, staff shortages, lack of confidence, privacy and signposting of resources. Facilitators were privacy for confidential discussions, training, confidence in knowledge and skills, and signposting of resources.

Conclusions: That so many busy CNSs completed this survey demonstrates the importance they attach to HNAs and COMPASS. The challenges faced with implementing these assessments into everyday practice require training, time, support services and an appropriate environment. It is vital that the HNA and COMPASS are conducted at optimum times for patients to make the best use of time and resources.

The impact of cancer and quality of life in head and neck cancer long-term survivors in the UK

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Background: Head and neck cancer (HNC) can have detrimental effects on patients' functioning and quality of life (QoL). The rising

incidence and survival rates in HNC result in an increasing population of survivors. It is thus important to understand their needs and experience, including positive aspects.

Aims: This study aimed to investigate (i) the associations of socio-demographic, clinical and psychological characteristics with positive and negative impacts of cancer (IOC) among HNC survivors, and (ii) the association between IOC and health-related QoL.

Methods: HNC survivors identified from the cancer registry of a London hospital completed validated measures of psychological distress (HADS), post-traumatic stress (PCL-C), social support (ESSI) and QoL (EORTC-QLQ-C30), as well as the Impact of Cancer scale (IOCv2). Demographic and clinical data were collected. Linear regression models were built to estimate associations with the IOC and QoL.

Results: At a mean of 7 years (SD = 5) after treatment (N = 93), the following risk factors were independently associated with negative IOC: psychological distress (Beta = .39, $p < .001$) and post-traumatic stress (Beta = .41, $p < .001$). Higher positive IOC was associated with greater time since treatment (Beta = .2, $p < .05$). Negative IOC scores were negatively associated with all EORTC-QLQ-C30 functioning scales and Global QoL. There was no significant association between clinical variables and IOC scores.

Conclusions: HNC survivors report both positive and negative impacts of cancer. Negative perceptions of cancer are strongly associated with poorer QoL. Screening for psychological distress, including post-traumatic stress, could identify those most in need of support and enable development of targeted interventions.

Optimising the care of patients receiving oral systemic anti-cancer treatments (SACT): the health professional perspective

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Presenting author: Michael Mawhinney

Background: Patients prescribed oral systemic anti-cancer treatments (SACT) need to be managed in accordance with national guidance to ensure safe and effective care. A regional cancer centre implemented a pharmacist and nurse-led oral SACT education clinic (OEC) providing individually tailored patient education about drug administration and side effect management.

Aims: This study aimed to identify what are the perceptions and experiences of health professionals involved in managing the care of patients receiving oral SACT?

Methods: Semi-structured interviews were conducted with 23 health professionals working with patients prescribed oral SACT. Health professionals included consultants (n = 6), pharmacist's (n = 5), a pharmacy technician (n = 1) and nurses (n = 11). Data were analysed using Framework Analysis (4).

Results: Patients were perceived to have greater control and autonomy about their treatment than patients receiving intravenous SACT. Oral SACT was incorrectly perceived by patients as less toxic than IV SACT. The OEC was viewed as an effective model of care. Participants recommended professionals in the OEC should be aware of 'information

overload' and the important role of family, friends and carers in ensuring safe administration. Some patients were perceived to be higher risk of adverse outcomes, highlighting the need for accurate assessment to stratify patients into risk groups to identify patients requiring closer monitoring.

Conclusions: Health professionals identified benefits and limitations to use of oral SACT. The OEC was perceived as an effective model of care to assist patients. Further research is required to explore the patient experience receiving oral SACT and the effectiveness of care interventions to manage this patient group.

Remembering friends: addressing bereavement support for teenage & young adults diagnosed with cancer experiencing the loss of a peer

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Background: The ethos of Teenage & Young Adult (TYA) oncology units encourage young people to engage in peer support during their cancer experience. However, when a young person dies their loss is felt considerably by other young people on the unit. Staff has observed an increase in TYA's communicating grief via social media. Without bereavement support young people are more at risk of experiencing psychological difficulties.

Aims: The aim of the project was to review current bereavement support, establish what support TYA's want and how to implement this support.

Methods: A patient group was established with 8 patients. The group discussed their own experiences of bereavement and bereavement support received. An online survey was created by the group and advertised on Facebook to establish wider opinions from other TYA's about bereavement and support services.

Results: Themes from the group and survey highlight that TYA's feel that death is a taboo subject, it created feelings of survivorship guilt and made them reflect on their own mortality. Of the 45 survey responses 89% of TYA's felt that they did not receive any bereavement support. 72% of patients felt that there should be an improvement in TYA bereavement services.

Conclusions: The project has highlighted the need to develop a formal TYA bereavement service. The group has organised their own yearly event to remember their friends which has run successfully for 2 years. Further developments include a space to reflect on the unit, and the development of a policy to improve how staff communicates the news of a death.

Exploring patient experiences of being diagnosed, treated and living with sarcoma—phase 1 in developing a sarcoma-specific patient-reported outcome measure

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Presenting author: Ana Martins

Background: Introducing patient-reported outcome measures (PROMs) into clinical practice is known to improve patient-clinician communication, patient experience and outcomes. While there are many generic cancer PROMs there are none developed for sarcoma so these may not capture issues that are tumour-specific.

Aims: To describe the experiences of being diagnosed, treated and living with sarcoma to inform the development of a PROM.

Methods: Participants across the UK were recruited by healthcare teams in Trusts or through the charities. Due to the heterogeneity of sarcoma, recruitment considered biometric factors, location of care, sarcoma type, treatment intent, treatment type, time since diagnosis, and other factors. Patients' experience was shared in semi-structured interviews and focus groups, which were transcribed and analysed using Framework analysis.

Results: A total of 120 patients participated [50% male; 13-82 years old; with soft tissue (62%), bone (28%) and GIST (10%)]. Five overarching themes were identified: impact of the diagnostic timeline (e.g. time to diagnosis, professionals' roles), physical wellbeing (e.g. mobility restrictions), emotional wellbeing (e.g. feelings of isolation), social wellbeing (e.g. impact on relationships) and financial wellbeing (e.g. challenges). The analysis identified the core experiences common to all sarcoma patients and the variances in reported experience depending on factors such as age and sarcoma type.

Conclusions: In the first step towards developing a sarcoma-specific PROM we have identified the key defining characteristics of patients' sarcoma experiences. While some were similar to experience in other cancer types, many were unique to this population. These will form the basis for content to be included in the PROM.

Developing a taxonomy of themes to drive improvements in the cancer patient experience that has meaning for both patients and professionals, as part of the PRESENT study

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Background: The National Cancer Patient Experience Survey (CPES) generates over 70,000 free-text comments annually, but with no

way of routinely and usefully analysing and reporting these. In the PRESENT study we developed machine learning to automatically sort these comments into themes and display them on a website. To enable comparisons across sites and over time, and to support healthcare professionals to improve the patient experience, the themes had to be fixed and to have meaning and salience for both patients and healthcare professionals.

Aims: To develop a taxonomy of cancer patient experience themes with names and definitions that have meaning for all relevant stakeholders.

Methods: We discussed themes from the cancer experience literature in innovative concept mapping workshops with patients, carers, healthcare providers, commissioners, and charities. Through facilitated discussions (recorded for further analysis) these negotiated theme names and definitions till they reached consensus.

Results: We held five workshops (34 participants). Each stakeholder type had a different understanding of the patient experience and priorities for change, but they reached consensus on 19 themes. The six most prioritised themes were referral from primary care and initial diagnosis; travel considerations; staff attitude and role (e.g. empathy from nurses who are expected to be caring); information for patients; patient's finances (e.g. claiming benefits); and hospital resources (e.g. broken equipment, lack of beds).

Conclusions: Patients and professionals were able to work together in the mixed stakeholder co-design style workshops. The taxonomy of themes they developed can be used to structure meaningful improvements in the cancer patient experience.

Psychological well-being in men with prostate cancer on Active Surveillance or Watchful Waiting: findings from a UK-wide mixed methods study (Life After Prostate Cancer Diagnosis)

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Presenting author: Eila Watson

Background: Over-treatment of men with prostate cancer (Pca) is of concern. Guidelines recommend Active Surveillance (AS) is offered to men with localised disease. As increasing numbers of men go on AS, developing a good understanding of the potential psychological implications of not being actively treated is essential.

Aims: To explore the psychological well-being of men with PCa on AS or Watchful Waiting (WW).

Methods: UK men diagnosed with PCa 18-42 months previously were invited to complete a survey, which included diagnosis and treatment information and measures of psychological well-being. The

psychological impact of being on AS/WW vs other treatments was compared, and factors associated with poor well-being explored. A sub-sample of AS/WW respondents were interviewed ($n = 24$) to understand their experiences in greater depth. Analysis used the Framework approach.

Results: 3,986/16,726 survey respondents diagnosed with localised disease were on AS/WW. There was no difference in overall well-being scores between men on AS/WW and those on active treatments ($t(df = 15,745) = -1.73, p = .08$). In men on AS/WW, unemployment, long-term conditions, deprivation and being widowed/single predicted poor well-being. Interviews indicated that most, but not all, participants had adjusted well. Men with poorer well-being seemed less able to accept and normalise the diagnosis and described receiving insufficient information and support, and a lack of confidence in their health care professionals.

Conclusions: Factors associated with good and poor adjustment to AS/WW indicate ways in which health professionals may improve the support to men on this pathway in the future.

Walk this way: learning from a feasibility RCT of a walking intervention for people with recurrent and metastatic cancer

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Presenting author: Jo Armes

Background: Walking is an inexpensive and accessible exercise. To our knowledge, no studies have investigated whether a walking intervention is sufficient to enhance quality of life and alleviate symptoms in people with recurrent or metastatic cancer across a range of tumour types.

Aims: To assess the feasibility/acceptability of undertaking an RCT of a community-based walking program to enhance quality of life and wellbeing in people with recurrent or metastatic.

Methods: Mixed-methods design including exploratory two-centre RCT, with randomisation between intervention and standard care. The intervention comprises information provision followed by a short motivational interview. Participants are asked to walk for 30-minutes on alternate days and attend weekly volunteer-led group walks. Questionnaires were completed at baseline, 6, 12 and 24 weeks. A sub-sample was interviewed at the end of the study.

Results: 42 participants were recruited, representative of the patient population. The intervention and study design were acceptable with

no adverse events. Some patients adapted the intervention to meet their own needs, for example, by continuing to walk with friends or relatives rather than the groups. There was an indication of good internal reliability for most outcome measures (Cronbach $\alpha > 0.80$), but the Scottish Physical Activity Questionnaire was found to be unacceptable to participants and yielded poor data quality.

Conclusions: The intervention was well tolerated and the study was acceptable/feasible. A full-scale RCT is warranted although participants could be offered more opportunity to tailor the intervention. Patients in the advanced stages of cancer highlighted the beneficial impact walking made to their well-being.

Does the EndoPredict test improve decision making about adjuvant chemotherapy in early stage breast cancer?

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Presenting author: Lucy Matthews

Background: Breast cancer treatment options can be complex to explain, patients may feel overwhelmed and pressured to make treatment decisions. Endopredict is a multigene profiling test which, together with clinical parameters (e.g. tumour size and nodal status), produces a score that classifies the risk of recurrence as low or high, in patients with early stage ER+ve, HER2-ve breast cancer.

Aims: To compare, patients' anxiety and decisional conflict, when considering treatment options [endocrine therapy (E) +/- chemotherapy (E + C)] before and after Endopredict testing. Oncologists' agreement and confidence about the decisions were examined.

Methods: Fourteen oncologists discussed the benefit of chemotherapy with 149 patients at 7 hospital sites. Provisional treatment decisions (E or E + C) were made based on standard clinical criteria; treatment decisions were reconsidered following Endopredict test results. Patients completed Spielberger's State/Trait Anxiety Inventory (STAI) and the Decisional Conflict Scale (DCS). Oncologists rated their confidence in agreement with the treatment decision pre- and post-test.

Results: Anxiety was stable in patients whose treatment decisions did not change following Endopredict test results. Anxiety significantly decreased in those whose treatment was downgraded from E + C to E ($p = 0.045$). Those who upgraded from E to E + C had increased anxiety ($p = 0.001$). Overall uncertainty on the DCS decreased post-test ($p = 0.023$). Oncologists' confidence about treatment decisions increased following test results, 8% 'strongly agreed' pre-test, 50% post-test ($p = 0.002$).

Conclusions: Patients were less conflicted about the treatment decision following Endopredict test results. Endopredict can be used to match therapy to risk allowing potentially better outcomes.

HORIZONS—results of the pilot phase of a study exploring the short, medium and long term consequences of a cancer diagnosis and cancer treatment

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Presenting author: Rebecca Foster

Background: The number of cancer survivors worldwide is increasing; however, the impact of cancer and its treatment on survivors' lives is not always well understood. A recent longitudinal cohort study of colorectal cancer survivors highlighted the particular challenges encountered by some patients. Results from similar cohort studies, involving other cancer types, will improve understanding of the impact of those cancer diagnoses and enable health professionals to tailor care to survivors' needs.

Aims: The HORIZONS programme is a longitudinal cohort study which will track the recovery of 3000 people diagnosed with breast cancer, non-Hodgkin lymphoma or a gynaecological cancer, from before primary cancer treatment, into follow-up and beyond. The pilot phase of the programme aimed to test the feasibility and effectiveness of study procedures and materials.

Methods: Details of the methods used in HORIZONS have been described elsewhere. The pilot phase of the study ran from September 2016 to May 2017.

Results: 24 sites opened to recruitment in the pilot phase of HORIZONS. 451 eligible patients were screened, of whom 389 (86.3%) were approached to take part and 281 consented (62.3%). Over 80% of baseline questionnaires were returned. Recruitment data, questionnaire data and participants' clinical details were analysed to assess feasibility and effectiveness.

Conclusions: During the pilot phase of HORIZONS participants were recruited to target, demonstrating the feasibility of the recruitment method. Valuable information gathered on other aspects of the study allowed the study team to refine and improve study procedures and materials.

Comparison of experience of patients with cancer of unknown primary (CUP) and known primary (non-CUP) amongst respondents to the Cancer Patient Experience Survey (2013)

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Background: Cancer of unknown primary (CUP) is the sixth most common cancer worldwide, accounting for 2.3%-5% of new cancers and 6% of cancer deaths. There is limited previous research exploring experiences of CUP patients.

Aims: To explore differences in experiences of care reported in the 2013 Cancer Patient Experience Survey (CPES) between patients with CUP and with metastatic disease of known primary (non-CUP).

Methods: χ^2 tests assessed associations between patient responses (CUP vs. non-CUP) to each CPES question. 'Small' or greater effects were classified as meaningful; corresponding to Cramer's $V > 0.7$. Free text comments from CUP respondents were analysed thematically.

Results: Matched analysis of closed response items from 2992 patients found meaningfully different comparisons between CUP ($n = 1496$) and non-CUP patients ($n = 1496$) for nine items, including CUP patients were more likely to want more written information about their type of cancer ($V = 0.123$) and tests received ($V = 0.102$), and to receive their diagnosis from a GP ($V = 0.104$), but less likely to understand explanations of their condition ($V = 0.076$), be involved with treatment decision-making ($V = 0.078$) or had surgery ($V = 0.124$). Free-text responses ($n = 3055$) provided deeper insight into responses. CPES data were unrepresentative of this patient population and may include a preponderance of patients with favourable CUP sub-types, and patients initially identified as CUP but whose primary was subsequently identified.

Conclusions: Findings indicate CUP patients may require more psychosocial support and specific interventions to manage diagnostic uncertainty and the multiple investigations many CUP patients face. Substantial limitations were identified with the CPES data, emphasising the need for prospective studies.

Supportive care needs of patients following diagnosis and treatment for colorectal cancer: results from the UK ColoRECTal Wellbeing Study CREW cohort study

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Background: Colorectal cancer (CRC) survivors might have specific supportive care needs which could be heightened during the transition period between treatment and recovery. The UK ColoRECTal Wellbeing study (CREW) is a large-scale cohort study investigating factors associated with recovery of health and wellbeing following curative-intent treatment for CRC.

Aims: To investigate unmet needs reported by patients with CRC at the end of treatment and whether these improve over time. To identify baseline predictors of need following treatment and implications of unmet need for recovery of health and wellbeing.

Methods: 872 adults undergoing curative surgery for CRC agreed to receive questionnaires pre-surgery, 3, 9, 15, and 24 months post-surgery which included assessments of health status, quality of life (QOL), well-being, social support and self-efficacy. The Supportive Care Needs Survey was completed by 525 patients at 15 months and 501 at 24 months.

Results: Prevalence of unmet needs was low (71% had no needs). Physical and psychological unmet needs were the most common and did not improve over time. Physical, psychological and health/information needs were predicted by baseline QOL. Sexuality, patient care/ support and health/information needs were predicted by age, cancer stage, QOL, negative affect and self-efficacy. Physical, psychological and health/information needs predicted overall health and QOL, after controlling for age, marital status and life events.

Conclusions: Around 29% of CRC survivors experience unmet needs in the two years following surgery which often persist over time and negatively impact QOL. Assessment and management of unmet needs should be integrated into patient-tailored survivorship care.

Exploration of the impact of the Penny Brohn UK Living Well Course on Cancer Survivors' employment and active community role status

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Presenting author: Helen Seers

Background: Over 750,000 people of working age in the UK are estimated to live with or beyond cancer, with 63,000 wishing to, but not working. Penny Brohn UK is a leading cancer support charity, offering the Living Well Course (LWC) which supports those affected by cancer to live healthy and active lives, including returning to work after cancer. No existing research has examined the impact of LWC on cancer survivors' employment or volunteering status to date. This study provides an initial exploration of the issue.

Aims: This study aimed to add to existing patient activation and patient-reported quality of life outcome evaluations of LWC by providing a 12-month follow-up to explore the long-term impact of LWC upon employment and volunteering status.

Methods: A mixed-method longitudinal design was applied with data collected at baseline, 6 months and 12 month follow up. Data from 43 clients were collected at 12-month follow-up using the PAM-10 and a bespoke Long-Term Follow-Up Questionnaire.

Results: Logistic regression showed statistically significant improvements in volunteering and employment status, as well as diet, exercise, relationships, utilisation of self-help techniques and patient resulting from attending LWC. A smaller non-significant result was found between levels of patient activation and employment and volunteering status.

Conclusions: Attending a Penny Brohn UK LWC had a significant positive impact upon volunteering and employment status of those who attended. This paper adds support for the use of holistic patient-centred interventions for improving employment outcomes for people living with and beyond cancer.

Developing and EORTC Survivorship Measure

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Presenting author: Teresa Young

Background: As more cancer patients are surviving longer it is important to have measures to assess their health related quality of life (HRQL) and late consequences.

Aims: To develop a provisional EORTC Survivorship Measurement system covering physical, mental and social HRQOL relevant to disease-free cancer survivors with diagnoses of breast, colorectal, prostate, bladder, gynaecological, head and neck, lung or testicular cancer or lymphoma, melanoma or glioma.

Methods: Phase 1a: We reviewed 134 cancer survivorship papers and interviewed 117 survivors, at least 6 months since completion of primary curative treatment, from 9 European countries (16 from the UK), generating a preliminary list of HRQOL issues.

Phase 1b: The list was shown and prioritised by 458 survivors from 14 countries (94 from the UK) alongside with the EORTC QLQ-C30 and validated EORTC site-specific modules.

Results: 1a: Mean age 57 (SD = 3.2), 54% were 2-5 years since completing treatment. 197 generic issues, 62 site specific issues and 8 sex specific issues were identified.

1b: Mean age 59 (SD = 13.8, range 28-85), 46% female. Average time since treatment was 3.6 years, range 0.5-26 years. The list was reduced to 117 generic issues plus 7-48 site specific issue per cancer site. Only 11 of the 30 items in the EORTC QLQ-C30 were retained in the 117 generic items. EORTC QLQ-C30 items for nausea/vomiting, appetite loss, constipation and diarrhoea and other acute symptoms were only prioritised by specific tumour groups.

Conclusions: A generic survivorship questionnaire is now being pilot tested across 11 tumour sites alongside site-specific modules for breast, colorectal and prostate cancer.