

BPOS Oral Presentations

Understanding pathways to diagnosis of a second primary cancer: Qualitative interviews with patients and GPs

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Background: More people are surviving a first primary cancer and experiencing cancer for a second time. However, little is known about the experience diagnosis of a second primary care (SPC), the implications for patient and professional awareness and referral for investigation and diagnosis.

Aims: To explore the views of patients and general practitioners (GPs) on experiences of SPC and the influence of a previous diagnosis of cancer on subsequent symptom interpretation, help-seeking behaviours, and referral decisions.

Methods: Semi-structured face-to-face interviews with patients with an SPC diagnosis, identified via the Scottish Cancer Registry, and case-linked GP interviews. Interviews were transcribed verbatim and subject to Braun and Clarke's thematic analysis. Two analysts read transcripts and developed the coding framework, assisted by QSR NVivo. Themes were developed from refined codes and interpreted in the context of existing literature and theory.

Results: Interviews were conducted with 23 patients (aged 43–84 years) with an SPC diagnosis, and 7 GPs. Preliminary analysis has led to the development of four themes: awareness of risk of SPC, Symptom appraisal and help-seeking, Emotional impact of SPC, Increased awareness and Fear of third primary cancer. GPs interviews echoed those of patients: GP awareness of SPC, Focus on recurrence, Noting FPC, and Referral for SPC.

Conclusions: Insights into the pathway to diagnosis of SPC, in the context of current understanding of cancer survivorship care, highlights the need for increased awareness among patients and professionals of the risk of SPC, and the need to ensure vigilance for second cancers as part of primary follow-up care.

Using the service user voice to co-design an end-to-end psychological support pathway for adults affected by cancer

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Background: Cancer and its treatments have the potential to significantly impact on mental health, affecting patient outcomes, experience and quality of life. Identifying psychological needs and providing high quality support is essential from diagnosis, through treatment, living with and beyond cancer and end of life care, but service users report gaps in service provision at vital points along the pathway.

Aims: The project aim was to co-design a flexible, responsive, user-centred, psychological support pathway across the whole system to improve outcomes, experience and quality of life.

Methods: Consideration of key national drivers, the literature and a mapping of current service provision in London, including psycho-oncology services, was undertaken. Two stakeholder events were held involving service users, health professionals and commissioners to identify current gaps in service provision and how to address these. Additionally, focus groups and qualitative interviews with adults affected by cancer were conducted.

Results: Thematic analysis from focus groups, interviews and stakeholder events identified key themes including:

- how to prevent distress and promote adjustment
- the need for better provision of information on local resources and sources of support
- the gap in psychological support post-treatment
- the expert role of psycho-oncology teams which should be available across the whole pathway
- the education and training needs of the wider workforce
- the wider impact on mental health of financial difficulties or fertility concerns.

Conclusions: This projects highlights the importance of listening to service users in all aspects of service design. A psychological support pathway with clear recommendations for commissioners on implementation has been developed for London.

Conceptualising dimensions of adjustment and self-management to advanced prostate cancer—A qualitative study

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Background: Some men living with advanced prostate cancer (PCa) can report comparable quality of life (QoL) to those with earlier stage disease.

Aims: To explore adjustment and self-management in men with advanced PCa in order to inform support services for men struggling with poor QoL.

Methods: Men were recruited through the "Life After Prostate Cancer Diagnosis" survey. Telephone interviews were conducted with 26 men in the UK with advanced PCa diagnosed 18-42 months previously. Thematic analysis was employed using the theoretical framework - *sense of coherence* (SOC) (Antonovsky, 1979).

Results: Many participants held a strong SOC regarding PCa and their lives, incorporating a sense of: a) *meaningfulness*, influenced by their sense of connectedness to others, orientation to life and engagement in valued activities; b) *manageability*, influenced by their level of confidence and motivation to manage PCa, level of support from health professionals, strategies to adjust (cognitive reappraisal, emotional coping) and having resources (social, financial), and; c) *comprehensibility*, influenced by the level of communication and information from health professionals (prognosis, future treatments), and ability to deal with uncertainty. Men with poorer adjustment reported a weaker SOC, greater severity of PCa symptoms and/or comorbidities, and greater feelings of loss and restriction.

Conclusions: Highlighting dimensions of positive adjustment to advanced PCa has implications for how men who are struggling could be better supported. Psychosocial interventions that identify and support men with a weaker SOC are required in order to improve men's QoL. LAPCD was funded by the Movember Foundation, in partnership with Prostate Cancer UK.

Acceptability and feasibility of a self-management intervention to improve adherence rates in women prescribed tamoxifen

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Background: Despite several studies highlighting the extent of non-adherence to tamoxifen in breast cancer survivors, interventions are currently lacking. A self-management intervention manual was developed based on the Intervention Mapping Framework and MRC guidelines. The intervention provided information on how tamoxifen works, remembering to take tamoxifen and managing side effects.

Aims: To test the acceptability and feasibility of this psychoeducational intervention and identify any changes to adherence or other key psychosocial variables.

Methods: The intervention was tested in a pre-post feasibility and acceptability study with 33 women prescribed tamoxifen scoring ≤ 24 on the Medication Adherence Rating Scale. The intervention lasted four to six weeks. Participants completed questionnaires pre- and post-intervention, including adherence, medication beliefs and quality of life. Eligibility, uptake and retention were recorded to assess

feasibility. Qualitative interviews assessed acceptability of the intervention materials.

Results: Recruitment and uptake were good, with 87% of eligible participants agreeing to take part. Around two thirds of participants recruited to the study completed the follow up questionnaires (66%). The qualitative interviews showed that the participants found the materials acceptable and helpful. Paired samples *t* tests showed small improvements in adherence over time, as well as larger improvements in necessity and concern beliefs, personal control, coherence, distress, symptom experience and self-efficacy for managing side effects.

Conclusions: The intervention booklet appears to be acceptable and feasible in this population and has the potential to improve both adherence rates and quality of life in breast cancer survivors prescribed tamoxifen. Larger scale trials are needed to establish the efficacy of the materials.

Using the cumulative model of patient complexity to understand supported self-management in older people living with multimorbidity and cancer: A theory-led qualitative systematic review

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Background: Cancer can be a substantial health challenge for older adults. It is often diagnosed in the context of, and thus complicated by, other complex health and social care needs.

Aims: We sought to explore how individuals balance the consequences of living with and beyond cancer against the wider demands of living with complex conditions and to identify the capacity of older cancer survivors with multimorbid conditions to handle the workload of disease management.

Methods: We conducted a systematic review of qualitative studies that reported on the experience of older adults self-managing multimorbidity and any cancer (PROSPERO Registration: CRD42018107272). A theory-driven coding framework was developed to analyse the qualitative data, based on the constructs outlined in Shippee's Cumulative Complexity Model: a patient-centred framework that emphasizes the workload-capacity balance of supported self-management, and incorporates treatment and illness burdens.

Results: Twenty-six papers were included. Older adults prioritise managing those conditions with (potential for) greatest functional impairment. It is often difficult to make sense of symptoms in the context of ageing, multimorbidity and cancer. The acceptance and normalisation of cancer may be facilitated by pre-existing chronic conditions and expectations of ageing. Patients' capacity to self-manage is influenced by personal beliefs, self-efficacy, and access to information and support.

Conclusions: This review offers an important insight into how co-existing comorbidities influence older cancer survivors' capacity to self-manage. The findings will inform the development of a targeted self-management intervention with older people after cancer treatment that focuses on those aspects that are amenable to change.

ACT-based therapeutic process changes and their association with patient-reported outcomes: Results from an international cancer survivorship cohort study

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Background: A growing literature demonstrates the effectiveness of Acceptance and Commitment Therapy (ACT) for cancer survivors. ACT increases psychological flexibility through changing acceptance, mindfulness, cognitive defusion and values-linked processes. Cross-sectional studies highlight significant correlation between some processes and patient-reported outcomes, but longitudinal data are lacking.

Aims: To explore prediction of patient-reported outcomes (distress, quality of life, benefit finding, fear of recurrence) from changes in ACT therapeutic processes.

Methods: 200 participants have been recruited using social media (Twitter, Facebook, Reddit). Our sample is demographically and clinically heterogenous. Participants complete online questionnaires every three months for two years. Questionnaires assess ACT processes and patient reported outcomes. Multivariate regression analyses are used to explore prediction of three-month patient-reported outcomes.

Results: Cross-sectional baseline analysis indicates high correlation between process and outcome variables. ACT processes remain statistically significant predictors of outcome, even controlling for demographic and clinical variables, using baseline (R^2 range = .168 to .560, $P < .001$) and 3-month (R^2 range = .205 to .435, $p < .05$) outcome data. Preliminary analysis indicates smaller effects of change in ACT processes on outcome: only the statistical model for perceived stress remained significant ($R^2 = .230$, $p < .05$).

Conclusions: Comprehensive theoretical modelling of longitudinal psychological adjustment is a necessary step in effective intervention development. These findings replicate and extend previous literature and demonstrate that experiential avoidance and values-linked processes may be especially pertinent predictors of later outcomes. Ground-up, data-driven approaches, will help us to develop more patient-led, clinically- and cost-effective interventions.

Patient, clinicians and trial staff views on the collection of patient-reported adverse events (AEs) in Early Phase Clinical Trials (EPCT): Phase 1 of the ePRIME study (electronic Patient self-Reported outcomes to Improve cancer Management and patient Experiences)

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Background: As new treatment options are developed for patients living with advanced cancer, the importance of adverse events (AE) reporting in early phase clinical trials (EPCT) is essential. Past research suggests clinicians underestimate AEs, and the value of patient-reported AEs has been emphasised.

Aims: To explore patients, clinicians and trial staff views of AEs in EPCTs, patient online self-reporting, and practical/ethical issues for a later pilot study.

Methods: Semi-structured audio-recorded interviews were conducted with 16 patients, 5 consultants, 4 research nurses, and 7 trial staff. Thematic analysis is ongoing but preliminary themes will be presented.

Results: All patients experienced AEs, but reporting to trial/clinical teams varied. Under-reporting mild symptoms and patient's waiting until their next appointment was apparent but the importance of comprehensive reporting/recording for safety purposes was emphasised by staff. 11 patients were willing to use an online AE system. Patient benefits included real-time reporting, and recording information for future patients. Reasons for not wanting to use a system included no internet ($n = 2$), feeling too well ($n = 1$) or unwell ($n = 1$). Staff benefits were real-time recording, prompting more information from patients, and capturing the breadth of lower grade (often unreported) toxicities. Practical issues included varying opinions between clinicians and trial unit staff on using real-time notifications, determining causality of toxicities and variable use of the internet.

Conclusions: Technology advances mean it is timely to explore the benefits/challenges of patient online self-reporting of AEs in EPCTs. We have developed an online patient symptom reporting tool and a small pilot is underway.

Communication by numbers

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Background: Conversations around cancer treatment and outcomes are often supported, if not driven, by numbers. This can clarify discussions, but may introduce ambiguity, particularly if communication is poor or the healthcare practitioner (HCP) overestimates a patient's literacy and numeracy skills.

Aims: The TARGET (Talking About Risk in the context of GENomic Tests) educational programme was designed to help HCPs discuss genomic test scores. Participants completed a numeracy worksheet to gain self-awareness of their own skill levels, the results of which are presented here.

Methods: 131 participants comprising oncologists, surgeons, and nurses completed a four-item numeracy test. This worksheet was collected across 9 TARGET workshops and seminars held at the 2018 Association of Breast Surgery and American Society of Clinical Oncology annual meetings. Respondents were asked to convert percentages, proportions and assess probability.

Results: Question success rates for the sample ranged from 94.7% when converting a percentage to a proportion, to 61.8% when calculating a proportion based on probability. All but 7 participants could calculate 1% of 1000 and 24 could not convert 1/1000 to a percentage. The biggest differences were seen between specialities, for example clinical oncologists had success rates between 65.5% and 100% while nurses ranged from 27.8% to 83.3%. This variability persisted across all four questions.

Conclusions: In an era of personalised medicine, both HCPs and patients are asked to assess likely outcomes based on numerical information that can be difficult to conceptualise. Our results indicate a need to ensure HCPs have further numerical training so as to provide appropriate patient-based communication.

OVPSYCH2: A randomised study of psychological support following chemotherapy for ovarian cancer

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Background: Fear of disease progression (FoP) is a rational concern for women with Ovarian Cancer (OC) and depression is a recognised risk. **Aims:** This randomised trial investigates the impact of a psychological intervention designed to manage help women identify, prioritise and manage the psychological concerns meaningful to them, including depression and FoP, to enhance QoL.

Methods: Women (pts) with primary or recurrent OC were eligible if they scored between 5-19 on PHQ9 immediately post-chemotherapy and randomised 1:1 to Intervention (3 standardised 90-minute psychological support sessions; 6-12 weeks post-chemotherapy) or

Control (standard of care). Unblinded block randomisation used for primary or recurrent OC; 3 levels of PHQ9 as stratification factors. Pts completed PHQ9, FoP-Q-SF, EORTC QLQ C30 and OV28 up to 2 years. Primary endpoint was change in PHQ9, 3 months.

Results: 182 registered; 107 randomised; 54 Intervention/53 Control; mean age 59; 75 (70%) primary/32 (30%) relapsed; 63 pts completed baseline and 3-month questionnaires: 31 control, 32 intervention. Improvement in PHQ9 for both arms at three months compared to baseline but no significant difference between Intervention and Control was observed. There was a significant improvement on FoP-Q-SF scores in the Intervention arm, whereas for pts in the Control arm, FoP-Q-SF scores deteriorated at 3 months (Intervention effect = -5.2, 95% CI (-8.45-1.9) $p = 0.003$. Psychologically-oriented QoL and body image significantly improved in the intervention group but not Global QoL.

Conclusions: Depression scores did not significantly alter at three months but significant improvement in FoP, emotional QoL and body image was observed.

Exploring men's experiences of caring for their partner: A longitudinal narrative study

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Background: Informal carers play a significant role in the care and support of people living with cancer. However, current understandings of the caring experience are predominantly based on research with women. Therefore, men's experiences of informal care are poorly understood. Understanding men's experience is important to ensure they receive the right support.

Aims: To explore the caring experience from the perspective of men. **Methods:** Data are drawn from a longitudinal qualitative narrative study involving 8 men interviewed on three occasions over 1 year. Preliminary findings draw on the first two interviews with 5 men aged 30-75 years old from Scotland. Care receivers were on average 9 months from diagnosis. Interviews were conducted between March 2017 and February 2019 and analysed guided by Riessman's approach to narrative analysis.

Results: Men frequently experienced multiple challenges including; giving up work to provide full time care, dealing with the loss of intimacy in their relationship and having no control over their partner's deteriorating health. They expressed helplessness and anger and tried to conceal their distress from others. Yet, for some, the act of caring brought purpose particularly when they were assisting with aspects of their partner's medical care in the home.

Conclusions: Male carers face specific challenges and benefits, such as dealing with a complex intertwining of positive and negative emotions that they may not feel they can discuss with others. Consequently, this study has shown specific dimensions of the male experience that need to be supported by professionals.

"You know it's not just a waste of time, somebody's looking at it." Patient engagement with online symptom reports during chemotherapy (eRAPID)—The importance of clinician use of data

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Background: eRAPID is an online system for patients to report and manage side effects during chemotherapy. Patients are asked to complete weekly symptom reports from home and receive automated tailored advice on managing symptoms. Responses are immediately documented in individual electronic records for clinician review during routine consultations.

Aims: To explore factors influencing patient engagement with eRAPID symptom reports.

Methods: A mixed method evaluation of patient engagement was integrated into a large scale RCT to evaluate eRAPID in systemic therapy (n = 354). Logistic regression was run to examine predictors of adherence to weekly symptom reports over the 18-week study period. A subset of patients were interviewed (n = 23) to further explore experiences. Triangulation techniques were used to compare and combine findings.

Results: 40% of patients were 100% adherent with a median adherence of 78%. In a logistic regression model, clinician use of patient data was the only significant predictor of adherence. This was supported by the qualitative data, with clinician use of data identified as a main motivator for sustained engagement. However, patient perceptions of clinician use of the data varied. When clinicians were clear and explicit with patients about their use of the data, patients were more engaged and felt their role was more valued.

Conclusions: Clinician engagement is intertwined with patient engagement and requires ongoing assessment to inform future development and implementation of systems.

Prevalence and risk factors of depression in colorectal cancer five years after surgery: Findings from the ColoRECTal Wellbeing (CREW) study

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Background: Cancer survivors face significant enduring psychological consequences, including depression, affecting quality of life (QoL) and well-being. Few studies have explored depression in colorectal cancer (CRC) in the long term and investigated risk factors which were assessed before surgery.

Aims: To describe clinical levels of depression in a CRC cohort up to 5 years following curative intent surgery and assess risk factors measured pre-surgery.

Methods: Recruitment from 29 UK centres resulted in 857 adults, treated surgically for non-metastatic CRC, consenting to follow-up. Questionnaires completed pre-surgery (baseline), then at 3, 9, 15, 24, 36, 48, and 60 months post-surgery, collected sociodemographic information and assessments of depression (Centre for Epidemiologic Studies Depression Scale, CES-D), anxiety, QoL, and well-being. Medical information was also collected. Longitudinal analyses assessed changes in clinical levels of depression (CES-D > 20) and associations between sociodemographic and clinical factors with psychosocial outcomes.

Results: The proportion of people with CRC assessed as clinically depressed peaked at diagnosis (21%). 15% remained clinically depressed up to 5 years after surgery. Clinical levels of depression were significantly associated with sociodemographic, but not clinical, characteristics. High levels of anxiety, low levels of self-efficacy, QoL and personal well-being at baseline were significantly associated with clinical levels of depression following surgery.

Conclusions: At diagnosis and at time points up to 5 years post-surgery, over a sixth of people studied had clinical levels of depression. This level and sustained prevalence suggests that screening tools should be introduced early in the care pathway, so patients can be quickly and suitably referred for appropriate early intervention.

Sexual dysfunction in men with prostate cancer: Access to and experiences of medication, devices, and support

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Background: Sexual dysfunction is a common challenge men experience after treatment for prostate cancer.

Aims: We explored men's access to and experiences of medications, devices and services to help with sexual functioning.

Methods: In a sub-study of a UK-wide survey of men 18-42 months post-diagnosis of prostate cancer, we explored responses to questions addressing access to and experience of medications, devices and specialist services in respondents who reported poor sexual function which they considered a moderate/big problem (EPIC-26). Free-text responses to an open question following this section of the survey were analysed using content analysis.

Results: 13,974 men (41.3% of overall sample) reported poor sexual function which was a moderate/big problem. 51% (7,027) were not offered any intervention to aid sexual functioning. Of men offered intervention who wanted/tried it, fewer than half found it helpful (49%, 2,367). Free-text responses revealed challenges with accessing help included; feeling “kept in the dark” by healthcare professionals regarding sexual aids/devices, and inadequate ongoing support/medication supply which was often “too little, too late.” Barriers to intervention uptake and raising concerns included; embarrassment, negative beliefs, polypharmacy, side-effects, disconnect between secondary and primary care services. “Drivers” to intervention use included proactivity, motivation and persistence, and ongoing support.

Conclusions: These findings highlight significant shortcomings in the help available to men with sexual dysfunction following prostate cancer. There is an urgent need for services to ensure men have access to appropriate treatments and support.

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Diet and nutrition support after a pelvic cancer diagnosis: A cross-sectional study in survivors 6-24 months post-treatment

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Background: A cancer diagnosis serves as a teachable moment for patients to consider lifestyle changes to cope with treatment and for

future health. Diet and nutrition is an important, yet neglected aspect of survivorship care.

Aims: This project aims to explore pelvic cancer (anal, bladder, rectal, and cancers of the reproductive organs) survivors' dietary habits and experiences of nutrition in cancer care.

Methods: Survivors of a pelvic cancer who completed radiotherapy treatment 6-24 months previously ($n = 405$) were invited to fill in a survey about their current dietary habits and dietary support received after diagnosis. Data were analysed using descriptive statistics and logistic regression.

Results: Respondents ($n = 152$; age range 30-92 years) reported high obesity rates (61.3% overweight/obese), presence of treatment side effects (77.9%) and comorbidities (77.0%). Two thirds of respondents (66.9%) reported at least one dietary change since diagnosis and 34% reported supplement use. Most notable changes included increased intake of fruit and vegetables and reduction of sugary foods and alcohol. Forty-one percent reported receipt of dietary advice from the healthcare team; mainly leaflets from cancer nurse specialists. Receipt of dietary support was a significant predictor of dietary change (OR 2.90, 95% CI: 1.36-6.21). Survivors were interested in receiving dietary support in relation to weight management, management of side effects and future health.

Conclusions: Results from this study highlight an increased need for dietary support in pelvic cancer populations post-treatment. Emphasis should be given to the role of the healthcare team in the delivery of nutritional information to influence patients to make healthy dietary choices.