BPOS

British Psychosocial Oncology Society

Annual Conference 2025

Holiday Inn Manchester - City Centre

Abstract Book

Contents

Oral presentations and Flash presentations listed in programme order.
Posters listed alphabetically by first presenter surname.

Thursday Presentations

Oral Presentations: Interventions in the healthcare setting

The golden thread: Co-designing a pathway between a Psycho-oncology and NHS Talking Therapies Service

Dr Emily Connolly[1], David Haylock
[1]Portsmouth Hospitals University NHS Trust, England

To meet the psychosocial needs of people affected by cancer, pathways are needed between specialist Psycho-oncology services and NHS Talking Therapies teams.

The Improving Psychological support for people affected by Cancer in Portsmouth service improvement project aimed to hear the experiences of people affected by cancer who have accessed a local Talking Therapies service or the local Psycho-oncology service as well as the experiences of staff. The project aimed to bring staff and people affected by cancer together to reflect on these experiences, identify problems, and generate solutions for a psychological support pathway.

An Experience Based Co-design (EBCD) methodology was used to meet the project aims. People affected by cancer were interviewed about their experiences, with the key themes from these interviews analysed and used to create a catalyst video. 11 staff were also interviewed, and key themes identified. The catalyst film was shown at a joint event for people affected by cancer and staff, where the 3 key priorities for the co-design phase were set. Co-design groups (consisting of staff and people affected by cancer) worked together to discuss improvements.

Results:
- Staff had limited knowledge of each other's services.
- People affected by cancer didn't feel their psychological needs were consistently recognised, understood, or supported from the point of diagnosis onwards.
- Talking Therapies staff expressed a range of concerns about working with people affected by cancer.

Conclusion: A number of service improvements were recommended:
- The development of an online place-based Cancer Psychological Support information hub, to contain information about local services, how and when they work with people
- Closer working links between Psycho-Oncology and Talking Therapies services, including the co-facilitation of interventions
- The development of a training package for Talking Therapies staff.
- The promotion of conversations about the psychological impact of cancer.

* * *

Best Practice Guidelines for Clinical Nurse Specialists supporting the psychological health of cancer patients: A Delphi Study

Dominique Cranstoun[1,2], **Dr Michael Baliousis**[1,3]
[1]University of Lincoln, Lincoln, [2]Lincolnshire Partnership Foundation Trust, Lincoln, [3]Nottingham University Hospitals NHS Trust

Background: Research has consistently reported high levels of psychological distress amongst patients with cancer, impacting quality of life, treatment success and survivorship, with many needs often being unmet. Clinical Nurse Specialists (CNSs) play a vital role in providing psychological support to patients with cancer.

Despite the growing recognition of their importance, there is limited consensus on best practice guidelines for CNSs in this context.

Aim: This study aimed to develop expert consensus-based best practice guidelines for CNSs providing psychological support to patients with cancer, using a Delphi method.

Methods: A preliminary phase included a literature review and interviews with 5 Clinical Psychologists experienced in cancer care to create an initial set of guidelines. A three-round Delphi study was conducted, involving a panel of 9 experienced CNSs and 11 patients with cancer. Data was analysed using descriptive statistics and qualitative analysis to identify themes and areas of agreement. Consensus was defined, a priori, at 75% and stratified into two tiers resulting in essential and important guidelines.

Results: The study identified 38 guidelines for effective psychological support in the themes of: aspects of communication, assessment and care planning, individualised care, training and development in problem-specific skills, building the therapeutic relationship, continued development and supervision, and training methods. Experts emphasised considerations for holistic patient care and the importance of integrating psychological care into routine practice.

Conclusions: The Delphi process resulted in clear guidance regarding what aspects CNSs may pay attention to in terms of best practice in providing psychological support in cancer care. These guidelines can serve as a framework for enhancing the quality of psychosocial care in oncology settings, both in terms of CNS practical skills and the wider frameworks supporting these.

……

Adapting and evaluating a 1:1 5-session fear of cancer recurrence intervention into a one-off group workshop for Barts Health patients

Dr Maggie Karanasiou[1], Dr Caroline Dancyger[1,2]
[1]Barts Health NHS Trust, UK, [2]North East London Cancer Alliance,

Background: Almost 73% of cancer survivors report some degree of fear of cancer recurrence (FCR) which, if untreated, can lead to worse patient outcomes and increased healthcare costs.
Conquer Fear is a recent intervention shown to reduce FCR for up to 6 months post-treatment. However, limited specialist psycho-oncology capacity for 1:1 interventions indicates that a stepped care model approach is necessary to meet patient needs more timely and reduce costs of untreated FCR.

Aims: The aim of this project was to adapt the 1:1 5-session Conquer Fear intervention into a one-off group workshop for cancer survivors with any degree of FCR accessing Barts Health, and to evaluate the initial feasibility, accessibility and efficacy of this workshop.

Methods: We delivered 9 iterations of the workshop to 70 attendees (M=7.8, SD=3.9) in North East London alongside Talking Therapy services over 19 months (May 2023 – November 2024). From the N=53 attendees who provided demographic information, 25% were male. Qualitative and quantitative feedback was collected after each workshop and analysed descriptively. An additional evaluation measure was completed from N=22 participants in the final 4 workshops.

Results: 97% of attendees (N=59) found the workshops helpful or very helpful, and 98% of attendees (N=55) said that it was likely or extremely likely to recommend the workshop to friends and family. Attendees highlighted the strategies and peer support element as the most helpful aspects of the workshop, and raised that having more time for group discussions would be helpful.

Improvements were noted in concerns about, understanding of, having tools to manage, and feeling confident in managing FCR, with small (dav=.25), medium (dav=.63) and large (dav=.82; dav=1.0) effect sizes respectively.

Conclusion: A one-off FCR group workshop appears to be feasible, acceptable and preliminarily efficacious to Barts Health patients. Suggested improvements include extending the workshop into 2-3 sessions.

……

Improving outcomes in psycho-oncology services through innovative service design and delivery: implementing and evaluating a new approach

Dr James Rathbone[1], Dr Sam Malins[1,2]
[1]Nottinghamshire Healthcare NHS Foundation Trust, England, [2]University of Nottingham, England

Background: Psychological therapy is effective at treating common mental health problems. However, in the past 40-years, overall recovery rates have not improved except in a few specific domains (e.g. Obsessive Compulsive Disorder) despite the development of multiple new treatment models. In the same period, cancer survival rates have improved dramatically. Prochaska, et al. (2019) proposed ways to improve effectiveness of psychological interventions, many of which have not been applied to cancer care but could support substantial improvements to care offered.

Aims: The East Midlands Cancer Alliance Centre for Psychosocial Health (EMCA CPH) focuses on improving cancer care in training, delivery of clinical services, and research. This paper presents initial evaluation of seven innovations implemented across the service to achieve marginal gains (Barkham, 2022) at specific points in a patient journey.

Methods: EMCA CPH has integrated and is evaluating these innovations; starting before the referral is received and continuing beyond discharge. Complimented with the use of low-resource technologies. This approach, shown to be successful in the field of medicine to improve cancer survive rates, has not previously been applied to psycho-oncology services.

Results: To date, an evaluation of a novel approach to delivering psychological skills training for cancer care staff demonstrated high skill acquisition for assessment and intervention with psychological distress, as well as improvements to staff's own well-being. Level 4 service drop-out rates are half of what is common in talking therapies, with clinical outcomes in the 99th centile when benchmarked against national statistics. A clinical trial focusing on a single session therapy preparation intervention is currently underway as well as an evaluation of innovations to prevent relapse.

Conclusion: Improvement in outcomes for psycho-oncology patients may be achievable by focusing on innovations that achieve marginal gains across the pathway. We present this new approach to designing and delivering psycho-oncology services.

……

Flash Presentations: Caregivers

The Psychosocial Impact of Pancreatic Cancer on Caregivers: A scoping review

Tara Anderson[1], Dr Gary Mitchell[1], Dr Gillian Prue[1], Dr Lisa Graham-Wisener[1]
[1]Queen's University Belfast, Northern Ireland

Background: Family caregivers are essential members of the care team of someone with pancreatic cancer, supporting their physical and psychological needs. Caregivers are often unprepared for this resulting in substantial psychosocial impact. The majority of people with pancreatic cancer are diagnosed at an advanced stage and are not eligible for potentially curative treatment. Therefore, caregivers may experience increased psychosocial impact due to the short life expectancy and rapid deterioration associated with pancreatic cancer.

Aim: A scoping review (ScR) was conducted to identify, from the existing literature, what is currently known about the psychosocial impact of pancreatic cancer on caregivers across the disease trajectory.

Method: A Joanna Briggs Institute (JBI) mixed methods ScR was conducted across four databases in March 2024 and reported in line with the PRISMA-ScR checklist. Included studies reported on the psychosocial impact of pancreatic cancer on caregivers. A deductive approach, guided by 'The Cancer Family Caregiving Experience' model (Fletcher et al., 2012), was taken to extract and synthesise the data.

Results: 39 studies were included: 21 qualitative, 13 quantitative, 5 mixed methods. The literature highlighted pancreatic cancer caregivers experienced stress related to caregiving activities, disruptions to daily life and family relationships, high levels of unmet need, and poorer quality of life compared to other cancer caregivers. They were also at increased risk for various psychiatric disorders. A persistent lack of support was reported which exacerbated the psychosocial impact.

Discussion: Pancreatic cancer caregivers experience negative psychosocial impacts, exacerbated by the disease's trajectory. Feelings of a lack of support were reflected throughout the included literature and emphasise the need for future research into how pancreatic cancer caregivers may be best supported, and sign-posted to existing support, to minimise the substantial psychosocial impact they may experience.

……

The impact of a cancer diagnosis on informal caregivers: findings from a multi-stakeholder, qualitative study and development of a tool kit for use by Health and Social Care (HSCP) Professionals

Lorraine Wright[1], Prof Nick Hulbert-Williams, Dr Brooke Swash, Prof Val Morrison
[1]Edge Hill University, Ormskirk, UK

Background: 1 in 2 people will develop cancer in their lifetime. There are 19 million informal caregivers in the UK. Thus, the number of caregivers with a cancer diagnosis (CWC) could be significant. The impact of caregiving whilst living with a cancer diagnosis is currently unknown.

Aims: This study generated evidence regarding the psychosocial impact of cancer on an informal caregiver to produce a toolkit for use by HSCPs in supporting this population.

Methods: Twelve semi-structured interviews were conducted with CWC and four focus groups with HSCPs. Results were analysed using reflexive thematic analysis.

The toolkit was developed using an experience-based co-design (EBCD) methodology. An initial version was developed through six workshops with CWCs and HSCPs. A series of iterative consensus events (four) with key stakeholders enabled the refinement and production of a toolkit for future trialling.

Results: Seven themes were identified from caregiver interview data, including identity, well-being, a changing role, dyadic illness, loneliness, family impact and new perspectives. The findings demonstrated that caregivers often struggle to navigate their caregiving role and their treatment, some even refusing potentially lifesaving therapies.

Three themes were identified from HSCP focus group data: care for self and others, psychological and physical impact and the CWC in health services.

These findings informed the production of a prototype toolkit that provides information about CWC's needs, challenges, and support or signposting that may be helpful to them. The toolkit is now ready for feasibility, usability, and implementation testing.

Conclusion: A limitation of this study is that we have focussed on CWC and HSCP perspectives. However, the findings extend current understanding of the impact of cancer on caregivers. With further testing, staff could use our toolkit to improve awareness, communication, and support for caregivers with a cancer diagnosis, eventually benefiting caregivers and health and social care services.

Oral Presentations: Adolescent and young adult cancer

Factors affecting psychosocial distress in adolescents and young adults with cancer: BRIGHTLIGHT longitudinal cohort study results

Dr Chana Korenblum[1,2], **Prof Rachel Taylor**[1,3], Dr Lorna Fern[1], Prof Rachael Hough[1,3], Dr Bethany Wickramasinghe[3], On behalf of the BRIGHTLIGHT study Group[1]
[1]University College London Hospitals NHS Foundation Trust, London, UK, [2]University of Toronto, Toronto, Canada, [3]University College London, London, UK

Background: Adolescents and young adults (AYA) with cancer face unique psychosocial challenges compared to younger children and older adults. There are little published data regarding the extent of psychological distress in AYA, particularly in large cohorts over time.

Aim: To explore relationships between distress and variables known to impact mental health, examine distress levels over time and to consult with an established group of AYA advisors to contextualize the results.

Methods: This was secondary analysis of the BRIGHTLIGHT dataset, a longitudinal cohort study, which recruited 830 AYA with cancer aged 13 to 24 years newly diagnosed with cancer, from 97 hospitals in England. The mean age was 20.1 (SD 3.3), 45% were female, with a range of cancer types. Psychosocial distress measured at five time points over 3-years following diagnosis. AYA impressions of study results were gathered from participatory workshops to inform conclusions.

Results: Social support significantly predicted distress scores (⍰= 0.202, $p<0.001$). Distress was found to decrease with worsening disease severity ($p=0.036$). AYA with and without a pre-existing mental health condition showed similar distress levels ($p=0.106$), while AYA with higher depressive symptoms were more likely to see a mental health professional ($p<0.01$). Across the five time points, anxiety symptoms remained stable ($p=0.090$), however, depressive symptoms improved ($p<0.001$). Seven workshop participants identified key relevant themes including the positive and negative effects of social support, as well as under-recognition and undertreatment of distress symptoms.

Conclusions: These findings, set in context by youth with lived experience of cancer, provide a deeper understanding of risk and protective factors for distress in a large, longitudinal sample of AYA. This information can inform the design of individualized, effective screening and interventions to mitigate distress and improve quality of life. Future research should include longer-term follow-up and prospective qualitative explorations of distress along the disease trajectory.

……

Social Transitions and Reintegration Support Programme (STARS): a mixed methods exploration of adolescent and young adult (AYA) psycho-social support needs following a cancer diagnosis

Dr Oana Lindner[1], Dr Angharad Beckett[3], Dr Rachel Taylor[4], Zoe Rogers[1], Dr Chris Bedding[1], Dr Richard Mattock[2], Dr Adam Martin[2], Dr Dan Stark[1]
[1]Leeds Institute of Medical Research, School of Medicine, University Of Leeds, Leeds, UK, [2]Academic Unit of Health Economics, Leeds Institute of Health Sciences, School of Medicine, University Of Leeds, Leeds, UK, [3]School of Sociology and Social Policy, University of Leeds, Leeds, UK, [4]Centre for Nurse, Midwife, and AHP-led Research (CNMAR), University College London Hospitals NHS Foundation Trust, London, UK

Background: The social lives of young people with a cancer diagnosis may be disproportionally affected compared to people of other ages and peers without this diagnosis.

Aims: The STARS Programme aimed to evaluate and compare employment, education, social, mental health and health-related quality of life (HRQOL) outcomes in AYAs diagnosed with cancer, to non-cancer peers aged 16-39.

Methods: Quantitative, longitudinal prospective survey data from BRIGHTLIGHT (2012-2015, N=830 aged 13-24, up to 3 years post-diagnosis), was complemented by the STARS prospective survey administered to a new set of participants (2020-2022, N=277, aged 16-39; either 6 months post-diagnosis or 3-5 years post-treatment). AYA patients were compared to matched non-cancer peers in the UK-representative UKHLS (‘Understanding Society’) survey (N=9,078). A nested qualitative sub-study complemented the quantitative findings.

Results: In BRIGHTLIGHT, within a year post-diagnosis AYAs were less likely to be in employment, education or training, and more likely to live in parental households and experience relationship breakdown compared to controls. Within 3 years, these differences decreased, but varied by age, gender, ethnicity, and cancer severity. Mental health and HRQOL improved for those with less severe cancers versus those with more severe diagnoses. In STARS, a large proportion of AYAs reported mental health problems, ongoing pain, and difficulties undertaking their usual activities, irrespective of the time since diagnosis. A large proportion of those in the early stages of their diagnosis (<3 years post-diagnosis) reported low HRQOL, felt limited in their activities, and reported financial struggles. Interviews identified themes related to ‘disruption’, ‘impact’, ‘support’and ‘reflections’. The common sub-theme was the unmet need for mental health support.

Conclusion: Mental health was participants’ highest concern. Patients recommended embedding mental health support as part of an extended and upgraded age-appropriate care pathway to help them adjust to social life following their diagnosis.

Flash Presentations: PROMs, PREMs and Psychosocial interventions

Increasing awareness of gynaecological cancer and early detection in students: pilot study of a university-based educational and behaviour change intervention

Dr Patricia Holch[1], Prof Anne Marie Bagnall[2], Seren Hughes[1], Dr Kate Liston[1], Dr Lauren McSorley[1]
[1]Psychology, School of Humanities and Social Sciences, Leeds Beckett University, UK, [2]School of Health, Leeds Beckett University

Background: Early diagnosis is key to improved gynaecological cancer (GC) outcomes and education is key to achieving this. Previously we found a sample of university students, could identify the red flag cancer warning signs, but were not able to identify less common signs. University is a key life transition, where positive health behaviours could be established. Therefore, we developed an intervention consisting of a bespoke online GC educational film and a volitional-help-sheet encouraging participants to self-monitor for gynaecological symptoms and identify cues to help-seeking/action.

Aims: To establish the feasibility and acceptability and barriers and enablers of intervention uptake for future implementation.

Methods: A longitudinal 1:1 randomised (intervention or control) online mixed methods design was employed. Eligible participants were students at risk of GC >18 at UK universities. Participants completed the Young Persons Cancer Awareness Measure and Theory of Planned Behaviour questionnaires at baseline, 4 weeks 3 and 6 months. Sixteen interviews were conducted with (n=14), participants, reflexive thematic analysis was employed.

Results: 110 participants (53 intervention; 57 control) 87% white British aged (M=22.75, SD=7.0) took part. Retention at 6 months was 37%. At baseline 83% overestimated their risk but only identified (M= 3.27, SD = 1.8) symptoms correctly. The interview analysis revealed the intervention was well received and students reported increased confidence in advocating for themselves. Participants stated: ‘this film should be everywhere’ and that it i)improved advocating for themselves, ii) enabled timelier help seeking for potential symptoms, iii) normalised the conversation and reduced stigma around GC and vi) increased help-seeking intentions and behaviours.

Conclusions: The feasibility and acceptability of the intervention was established and students found the film and volitional-help-sheet useful. The barriers and enablers to uptake were identified and these important learnings will be used to improve the intervention to develop a definitive study across UK Universities.

* * *

Reducing anxiety and creating coping mechanisms through a reflective reframing exercise "The Map"

Lidia G. Stoica[1], Maria V. Uta[1], Anamaria Ciubara[2], Enache Tusa[3]
[1]Association Of Patients With Chronic Diseases Restart To Life, Bucharest, Romania, [2]Dunărea de Jos University of Galati, Faculty of Medicine and Pharmacy, Department of Psychiatry, Galati, Romania, [3]Ovidius University of Constanța, Faculty of Psychology and Educational Sciences, Constanta, Romania

Context: Cancer associated a significant challenge both physically and psychologically. Anxiety, a common symptom in cancer patients, with significantly affects.

Objective: This study aimed to evaluate the effectiveness of a reflective reframing exercise in reducing anxiety and creating coping mechanisms in patients diagnosed with cancer.

Method: An experimental design with randomized control group and repeated measures was used. The sample comprised 60 women (20 -72 years), diagnosed with various types of cancer (breast, Hodgkin's, colon, cervical, liver), from urban and rural areas. The participants were randomly assigned into two groups: the experimental group (N=30), which received an individual intervention based on reflective reframing exercises, and the control group (N=30), which was placed on a waiting list. The study had a longitudinal design with data collection at baseline, 4 weeks and 8 weeks.

Intervention: The reflective reframing exercise included cognitive behavioral therapy techniques, visualization and metaphors, structured in five phases: introduction, reflection, reframing, goal setting and conclusion. Sessions lasted 45-60 minutes, tailored to the individual needs of the patients.

Measurement instruments: The Generalized Anxiety Disorder Scale (GAD-7) was used to assess anxiety, and the Functional Assessment of Cancer Therapy-General (FACT-G) was used to assess quality of life.

Results: The experimental group showed a significant reduction in anxiety compared to the control group. There was also an increase in quality of life, manifested by an increase in satisfaction and a more positive perception of the future among participants in the experimental group.

Conclusions: The study emphasizes the therapeutic potential of reflective reframing exercise in managing anxiety and developing the development of psychological coping with illness in cancer patients. The obtained results open perspectives for the development of integrated psychological interventions in oncologic care with the aim of improving patients' quality of life.

Keywords: cancer, anxiety, reflective reframing, cognitive-behavioral therapy, quality of life

……

Evaluating the Psychometric Properties of the Benefit Finding Scale: A Factor Analysis and Item Response Theory

Kian Hughes[1], Prof Nicholas J. Hulbert-Williams[1], Prof Mark J. Forshaw[1], Associate Prof Lisa Beatty[2], Dr Lee Hulbert-Williams[1]
[1]Edge Hill University, UK, [2]Flinders University, Australia

Objectives/Background: While some individuals report positive psychological changes, such as benefit finding, following a cancer diagnosis, inconsistencies in findings across studies raise questions about the reliability of measurement tools. The Benefit Finding Scale (BFS), a widely used measure, has been criticised for conceptual overlap with related constructs, such as post-traumatic growth, and for demonstrating substantial floor effects. This study aims to evaluate the psychometric properties of the BFS to determine its reliability and validity as a measure of benefit finding.

Methods: Data collection began in October 2023, and to date, 300 participants have been recruited through online platforms (e.g., Prolific, social media sites), with a target of 500 participants anticipated by the end of December 2024. The BFS was administered alongside measures of related constructs (e.g., post-traumatic growth, happiness, optimism, satisfaction with life) to assess concurrent and discriminant validity. Data analysis is currently ongoing, employing factor analysis to evaluate the underlying structure of the BFS and Item Response Theory approaches to examine item-level characteristics.

Results: Preliminary analyses demonstrated that a unidimensional model offered a poor fit to the data. Instead, the results supported a multidimensional, four-factor structure that appears to provide a more coherent and meaningful representation of benefit finding. These findings suggest the BFS captures multiple distinct aspects of positive change, offering a more nuanced understanding of benefit finding.

Conclusions and clinical implications: Despite its widespread use, the BFS has faced criticism for potential psychometric limitations, including concerns about its dimensionality. Refining the BFS's factor structure improves its utility as a measure of benefit finding and informs psychosocial interventions to better support individuals living with and beyond cancer.

……

Supporting women with breast cancer with adherence to adjuvant endocrine therapy (SWEET): a feasibility study of the HT&Me intervention

Prof Eila Watson[1], Dr Lucy McGeagh, Dr Sarah-Jane Stewart, Dr Ruth Norris, Prof Linda Sharp, on behalf of SWEET Research Team
[1]Oxford Brookes University, Oxford, UK

Background: Adjuvant endocrine therapy (AET), taken daily for 5-10 years, is effective in reducing the risk of breast cancer recurrence, yet adherence is known to be sub-optimal. Determinants of adherence include medicine-related (eg side-effects), healthcare-related (eg relationship with health professionals) and patient-related (eg. beliefs and concerns) factors.

Aim: To assess the feasibility and acceptability of delivering an evidence-based, theory-informed intervention (HT&Me) to support women with AET adherence and improve health-related quality-of-life.

Methods: Women within 14 weeks of being prescribed AET following a primary ER+ve breast cancer diagnosis, from 5 NHS hospital sites in England were enrolled. All received a personalised intervention comprising: 1) an animation video about AET; 2) two personalised AET consultations with a study nurse/practitioner (face-to-face in the treating hospital or remotely through the charity Breast Cancer Now); 3) access to an interactive web-app (including information, support and interactive tools to support adherence); and 4) motivational nudge messages. Participants completed a baseline questionnaire, and a follow-up questionnaire at 8 weeks. A sub-sample of participants and health care professionals (HCPs) were interviewed to explore experiences of the intervention and study participation.

Results: 51 women received the intervention. Participants were diverse and included some (28%) who were not confident in using IT. Completion rates of study outcome measures were high. All found the intervention to be acceptable and perceived it to be useful. Both face-to-face and remote delivery of consultations was acceptable and intervention delivery was feasible. HCPs were positive about the study and felt it was addressing a significant need.

Conclusion: Findings informed minor adaptations to the intervention and a large-scale randomised controlled trial is now underway to evaluate clinical and cost-effectiveness of HT&Me. The intervention offers potential to improve patient outcomes by increasing adherence and thus reducing risk of recurrence.

……

Implementing Patient-Reported Outcomes to Enhance Head & Neck Cancer Care: A Quality Improvement Project

Dr Jenny Harris[1], Zoe Clothier[1], Mandeep Bajwa[1,2]
[1]University of Surrey, Guildford, UK, [2]Royal Surrey NHS Foundation Trust, Guildford, UK

Background: Patient-Reported Outcomes Measures (PROMs) are increasingly important in modern oncology care, offering insights into care quality, patient experiences, and clinical outcomes. Despite strong evidence of their benefits, integrating PROMs into routine NHS practice is hindered by cultural resistance, workflow inefficiencies, and workload challenges. A shift towards patient-centred, PROM-guided care may improve patient outcomes and reduce healthcare costs but it is essential to better understand how to implement them effectively in real-world settings.

Aims: This project aimed to implement a customised PROM platform for Head & Neck Cancer (HNC) patients at the Royal Surrey NHS Foundation Trust (RSFT), identify barriers and enablers to adoption, and evaluate its impact on patient and clinician outcomes using Implementation Science methodologies.

Methods: We collaborated with "My Clinical Outcomes" to implement a tailored online PROM platform. Implementation involved staff training, workflow integration, and longitudinal data collection. Mixed-methods evaluations include:

1. Pre- and post-implementation snapshot audits of outpatient appointments and hospital admissions.
2. PROM data and service assessments (including patient satisfaction) and case studies.
3. Administrative data from the PROM platform tracking patient engagement and data completeness.
4. Semi-structured interviews with healthcare professionals (HCPs) exploring barriers, enablers, and longitudinal shifts in perceptions.
5. Quantitative and qualitative analyses of patient-reported Quality of Life (QoL) outcomes.

Results: Preliminary baseline data reveal variations in outpatient appointments, emergency admissions, and service use. Early engagement with patient highlights a strong willingness to adopt PROM-guided care and openness to using PROMs, citing their relevance to improving care quality, though staff express concerns about workflow integration and resource constraints.

Conclusion: While results are pending, initial data collection and stakeholder engagement indicate promising readiness for PROM-guided care. This project lays the groundwork for evaluating the long-term impact of PROM implementation on patient-centred care and clinician support, offering a potential model for wider adoption.

……

From Treating to Preventing Distress in Psychological Prehabilitation – A Novel Theoretical Framework

Dr Michael Baliousis, Dr Christopher Meek, Dr Lauren Heathcote, Dr Chloe Grimmet, Prof Nima Moghaddam, Prof David Dawson, Dr Mike Rennoldson
[1]Nottingham University Hospitals NHS Trust, UK

Background: Cancer treatment poses significant psychological challenges, with many patients experiencing distress from both anticipated and actual treatment demands. Psychological support remains largely reactive, while prehabilitation for cancer treatment (PPCa) offers a unique opportunity to prevent distress by preparing patients for these stressors. However, the absence of a comprehensive theoretical framework has limited PPCa's preventative potential.

Aims: This paper presents a novel theoretical framework integrating key psychological theories to guide PPCa. It aims to bridge gaps in preventative care by addressing PPCa's distinctive role: preparing patients psychologically for the stress of treatment.

Methods: A theoretical synthesis approach was employed, identifying five key psychological domains relevant to PPCa: stress and resilience, social identity, affective forecasting, stress inoculation, and narrative identity. These were integrated into a model to guide both research and practice.

Results: The framework considers patients' resilience resources, experiences, and social identities alongside their treatment anticipations (affective forecasting). It guides strategies to adjust forecasts, integrate existing and new resources, and build future-focused, recovery-oriented toolkits and self-narratives. Practical applications span universal, targeted, and specialist levels of prehabilitation, aligning with National Guidelines. The model has the potential to enable personalised interventions addressing individual patient-stressor profiles to enhance psychological readiness for cancer treatment and optimise recovery.

Conclusion: This framework represents a critical advancement in PPCa, shifting focus from reactive treatment of distress to proactive prevention. By equipping patients with tailored psychosocial resources, it aims to enhance readiness for cancer treatment, with the potential to optimise recovery. Future research should evaluate its mechanistic pathways and clinical impact to refine its application in diverse healthcare settings.

……

Oral Presentations: Risk, screening and inequalities

Real-world evaluation of a patient decision aid for genetic cancer risk management to inform optimisation before implementation, with implications for improved risk communication in clinical practice

Kelly Kohut[1,2], Dr Rebecca Foster[1], Lesley Turner[3], Dr Kate Morton[1], Dr Helen Hanson[4,5], Dr Katie Snape[2], Prof Diana Eccles[1], Prof Claire Foster[1]
[1]University Of Southampton, UK, [2]St George's University Hospitals NHS Foundation Trust, UK, [3]Patient and public collaborator, UK, [4]Royal Devon University Healthcare NHS Foundation Trust, UK, [5]University of Exeter Medical School, UK

Background: Genetic cancer predisposition carriers face complex, time-sensitive choices about risk management. To complement genetic counselling, a prototype decision aid was codesigned and iteratively refined based on interviews and patient and public involvement (PPI), guided by the Person-Based Approach and the Medical Research Council Framework on developing complex interventions.

Aims: Evaluation survey to address the research question:
How does the optimised decision aid meet the needs of a large, real-world sample for information, engagement, acceptability and decision support?

Methods: A digital survey was codesigned with PPI to optimise wording and recruitment strategy. Carriers and their relatives were invited through community advertisements or their genetics service. Respondents were asked to rate the decision aid overall, for ease of understanding and use and whether they would recommend it. Free text comments were invited. Data was analysed using descriptive statistics and content analysis.

Results: n=66 respondents from various geographical locations completed at least 50% of questions, including 47 (72%) females and 19 males aged 18-25 to over 70 years. Almost half had a personal history of cancer. Most rated the decision aid highly, 97% ‘helpful’, 96% ‘easy to understand’, 96% ‘easy to use’ and 91% indicated they would recommend it. Comments included ‘I cannot believe how helpful and reassuring this has been’ and ‘very informative, happy, my grandchildren can be more knowledgeable’. Health literacy levels were high, with 70-85% confident accessing medical information.

Conclusions: Respondents from a range of locations and backgrounds rated the decision aid positively, confirming wider acceptance of previously codesigned content. Survey findings informed final optimisation including wording changes and adding links to support. This real-world evaluation provided insight into how the decision aid would be used before implementation as a scalable decision support resource, with broader implications for clearer, more personalised genetic cancer risk communication in clinical practice.

* * *

Unmet psychosocial needs in cancer care: Understanding inequalities in access to cancer care for Asian women in 2024

Raffa Tate[1], Eamon O'Reilly
[1]Chelsea and Westminster Hospital NHS Foundation Trust (Chelsea & Westminster), London, UK

Background: Between 1971 and 2017, the UK saw a significant increase in newly diagnosed cancers, rising with a growing ethnically diverse population.

Despite efforts to improve healthcare access, the NHS's engagement with all minorities has not been equal. Indian communities, in particular, still face barriers to psychological support due to mental health stigma, cultural misconceptions, language barriers, and societal pressures.

Aims: This project aimed to highlight the poorer experiences of ethnic minority cancer patients, particularly from Indian backgrounds. It provided the NHS with a model for engaging these minorities, analysed the drivers of their challenges, and offered recommendations for improving care through effective patient engagement and understanding their coping mechanisms.

Methods: This study investigated a pilot successful intervention comprising educational lectures and peer mentoring through culturally competent face to face Cancer Support Groups (CSGs) for Asian breast cancer survivors from 2022 to 2024 at a London NHS Trust. The first phase involved gathering feedback from Asian patients over two years regarding their coping mechanisms and the challenges they face in accessing healthcare. The second phase consisted of in-depth interviews with five patients, exploring the role of the stigma, family, heritage on their treatment decisions.

Results: This study, involving 50 breast cancer patients from Indian communities, identified challenges in six areas: safe spaces for sharing, communication tools, stigma affecting healthcare, coping with treatment, tradition's impact on treatment choices, and family dynamics. Recommendations for improving NHS engagement emphasize addressing language barriers, societal stigmas, and promoting inclusivity.

Conclusion: The findings reveal that many patients delayed seeking breast cancer diagnoses due to lack of awareness and psychological stigma, including misconceptions about the disease. The author emphasizes the need for culturally sensitive interventions for Asian breast cancer survivors, advocating for stress management, peer mentorship, and culturally competent care to improve healthcare access.

……

Reducing barriers to cervical screening for autistic people and people with learning disabilities

Dr Janine Owens[1], Dr Lorna McWilliams[1], Dr Melissa Kirby[1]
[1]University Of Manchester, Manchester, UK

Throughout the UK only 30% of autistic people and people with learning disabilities attend for cervical screening compared to 75% of the general population. The range of abilities possessed by autistic people and people with learning disabilities makes reducing barriers challenging. Two of the largest challenges are facilitating accessible information to enable informed choice and decision-making and raising awareness of their needs with the staff within the cervical screening programme.

Aims: After discussions with autistic people and people with learning disabilities using involvement methods, the aim was to co-produce videos about cervical screening for autistic people, people with learning disabilities and staff to assist cervical screening.

Methods: Co-production, using inclusive creative methods, was used with a team of three people with learning disabilities and autism, one person with autism, their support and a researcher to develop a series of short videos. A further co-produced video was developed for vaccination for HPV in Urdu. 7 Urdu speaking mothers of autistic children and children with learning disabilities, an interpreter and 2 researchers participated in the latter.

Results: Developing videos with autistic people and people with learning disabilities plus Urdu speaking parents exhibited benefits in the development of reciprocal and collaborative relationships with clinical and community partners. For the parents, the range of views on the area meant careful negotiation by the researchers whilst considering cultural sensitivities. Working with people with learning disabilities and autistic people meant developing relationships and rules first before proceeding to developing the videos. The video for staff on the cervical screening pathway is currently being empirically evaluated.

Conclusion: Using co-production and creative methods produces more accessible information. This enables choice and decision-making by marginalised and excluded groups whose voices are often excluded from cancer research.

……

Friday Presentations

Flash Presentations: Understudied and advanced cancer

A Qualitative Systematic Review of the Psychosocial Aspects of Living with Pancreatic Cancer

Lana Cook[1], Dr Gary Mitchell[1], Dr Gillian Prue[1]
[1]School of Nursing and Midwifery, Queen's University Belfast, Belfast, Northern Ireland

Background: Despite improvements in the survival of many cancers, there has been little progress in pancreatic cancer outcomes due to difficulties in screening and early detection. Five-year survival rates are less than 5% overall and below 1% for inoperable tumours. Consequently, people diagnosed often face significant psychosocial challenges. However, research on these aspects of people's pancreatic cancer journeys remains scarce globally. Therefore, this review seeks to deepen understanding of the experiences of people with pancreatic cancer in this area.

Aims: To identify, analyse and synthesise empirical literature which answers the primary research question: 'What are the psychosocial aspects of people's experiences when receiving, living, and dying with (or surviving) a pancreatic cancer diagnosis?'

Methods: This qualitative systematic review observed PRISMA 2020 guidelines. CINAHL, Embase, MEDLINE, PsycINFO, Scopus, Web of Science, and the WHO Global Index Medicus databases were searched from inception until August 2024. 6,433 records were identified and 25 studies met inclusion criteria.

Results: Four key preliminary themes emerged: (1) psychological distress relating to three sub-themes: a) the shock of diagnosis, b) fears and uncertainty, and c) changes in identity and social roles; (2) the impact of symptom experiences on quality of life and social life, especially gastrointestinal issues secondary to pancreatic exocrine insufficiency; (3) coping mechanisms and sources of support, relating to three sub-themes: a) family support, b) hope, faith, and spirituality, and c) the health care team; and (4) information needs, communication, and decision-making.

Conclusion: This review emphasises the profound psychosocial challenges faced by people with pancreatic cancer and highlights the importance of interventions which address psychological distress, improve quality of life, and support coping mechanisms. Insights from this review can guide future research and inform the development of interventions which better support people navigating the complexities of a pancreatic cancer journey and meet their psychosocial needs.

* * *

Life after endometrial cancer: exploring the survivorship-related psychosocial needs of survivors

Humairaa Daud[1], Dr Esther Moss[1], Kshama Patel[1], Dr Gianina-Ioana Postavaru[1]
[1]College of Life Sciences, University of Leicester, Leicester, UK

Background: Fear of Cancer Recurrence (FCR) is a psychological consequence of a cancer diagnosis, affecting over half of cancer survivors. Endometrial cancer (EC), or womb cancer, is the most common gynaecological cancer in the UK however, FCR and the survivorship-related psychosocial needs of survivors are often overlooked. Reasons for this include a high proportion of early-stage diagnosis and good prognosis cases.

Aims: To investigate survivorship-related challenges and FCR experienced by EC survivors, given the rising EC incidence, especially amongst younger women.

Methods: Women who had completed curative primary treatment for an EC, and who lived in England were invited to participate in an individual semi-structured interview. The topic guide included discussion of their experiences of diagnosis, treatment and survivorship, including general health and fitness and future health concerns. Interviews were transcribed verbatim and analysed using reflexive thematic analysis to explore experiences with survivorship challenges and FCR symptoms.

Results: In total 21 women participated in an interview. The median age of participants was 56, range 43-71 years. The majority of participants were of White ethnicity (17 White: British and 2 White: Other White) and two were of Asian/Asian British ethnicity. Analysis of the interviews identified three main themes: cancer experience; fear of recurrence; and survivorship. One factor that contributed significantly to psychological challenges was treatment-induced menopause. A perceived lack of post-treatment care and knowledge of available support accentuated feelings of isolation. FCR was reported frequently, resulting in increased anxiety and hypervigilance of symptoms. Younger age at diagnosis appeared to exacerbate and lengthen the experience of FCR.

Conclusions: Despite EC being associated with a high cure rate, a large proportion of survivors still experience life-changing psychological sequalae, in particular FCR. Further research is needed to design tailored support services to address the psychosocial impact of an EC diagnosis and treatment.

……

Psychological profile of patients with sarcoma in the UK

Dr Tim Cartwright[1], Prof Nicholas J. Hulbert-Williams[1], Dr Lesley Storey[3], **Prof Rachel M. Taylor**[2], **Dr Lee Hulbert-Williams**[1]
[1]Edge Hill University, Ormskirk, UK, [2]University College London, UK, [3]Anglia Ruskin University, UK

Background: Sarcoma is a rare cancer affecting connective tissue, affecting approximately 5,000 people in the UK annually. It can present anywhere in the body and is typically delineated as affecting soft tissue or bone. It can occur at any age and has high treatment burden, with lower survival rates than other cancer types. Furthermore, there is high rate of recurrence and metastasis; patients remain in follow-up for many years. We have previously demonstrated higher rates of fear of recurrence (FCR) than reported by patients with other cancer types.

Aims: To describe psychological outcomes according to clinical factors in patients with sarcoma.

Methods: UK patients with sarcoma were invited to participate in an online survey, circulated through charities and social media. Self-reported measures captured FCR, anxiety, depression, stress, perceived physical impact of sarcoma, and quality of life (QoL). Data were analysed to explore differences between variables using t-tests and ANOVA.

Results: A total of 229 people with sarcoma returned the survey (age M = 52.5, SD = 14.7) comprising 168 (73%) females, 166 (72%) married, and 104 (47%) in employment. Types of sarcoma included 167 (74%) soft tissue, 33 (15%) gastrointestinal stromal tumour, and 25 (11%) bone tumour. Fifty-three (23%) had a recurrence and 58 (25%) metastases. There was no relationship of recurrence, metastasis, and surgery as treatment or amputation with QoL, anxiety, depression, or stress outcomes. Type and location of sarcoma predicted anxiety and depression respectively, as well as functional disability. Both experience of recurrence and female gender predicted higher FCR.

Conclusion: This research provides useful exploratory data about the psychological profile of patients with sarcoma and which factors might predict negative outcomes. This information is important in helping to develop targeted psychological interventions.

……

Head and Neck Cancer and Work Engagement: A Study of Return to Work (RTW) Outcomes

Emma Kinloch[1]
[1]Birkbeck College, London, UK

Background: The incidence of head and neck cancer (HNC) is rising, with increasing numbers of younger, working-age individuals affected. The rates of return to work (RTW) after HNC diagnosis and treatment are lower compared to other cancer types. RTW after cancer treatment benefits the individual and society.

Research indicates that the physical and psychological effects of HNC treatment contribute to these lower RTW rates. While studies have identified specific barriers to RTW for HNC patients, there has been little focus on examining how RTW is addressed by healthcare professionals (HCPs) or employers.

Aims:
- To explore whether HNC patients are being engaged in discussions about RTW by HCPs and/or employers.
- To assess whether discussions impact the RTW outcomes of HNC patients.
- To identify and document the specific challenges HNC patients face in returning to work.

Methods: An online survey consisting of 34 closed and open-ended questions was distributed to HNC support groups, clinical teams, and charitable organisations November 2020 -March 2022. Two RTW variables were analysed: time taken to RTW, and type of work after RTW. Data was analysed via descriptive and inferential statistics, as well as content analysis.

Results: A total of 152 respondents were included in the analysis. Nearly one-third of participants reported that RTW was not discussed with either their employer or HCP. Significant differences were observed in the time taken to RTW when HCPs or employers initiated RTW discussions. Additionally, the type of work patients returned to was significantly associated with whether RTW discussions took place with employers.

The most common HNC-related effect impacting RTW was speech and communication issues.

Conclusion: There is a lack of consistent and formal discussions about RTW between HCPs and employers, and HNC patients, which impacts RTW outcomes. The specific effects of HNC have the most impact on RTW.

……

Experience of participating in a randomised controlled feasibility trial of surgery versus no surgery as part of multi-modality treatment in stage III-n2 non-small cell lung cancer

Dr Sally Taylor[1,2], Melissa Perry[1], Ashleigh Ward[1], Emily Harris[1], Dr Selina Tsim[3,4], Dr Neal Navani[5], Prof David Baldwin[6], Dr Ian Woolhouse[7], John Edwards[8], Dr Seamus Grundy[9], Dr Jonathan Robson[10], Dr Sarah Rhodes[11], Nathan Burnside[14], Prof Fiona Blackhall[11,12], Prof Corinne Faivre-Finn[11,12], Prof Janelle Yorke[1,2], Dr Matthew Evison[13]
[1]Christie Patient Centred Research, The Christie NHS Foundation Trust, UK, [2]School of Nursing, Midwifery and Social Work, University of Manchester, UK, [3]Glasgow Pleural Disease Unit, Queen Elizabeth University Hospital, , UK, [4]Institute of Cancer Sciences, University of Glasgow, UK, [5]Lungs For Living Research Centre, University College London and Department of Thoracic Medicine, University College London Hospital, UK, [6]Respiratory Medicine Unit, David Evans Research Centre, Nottingham University Hospitals NHS Trust, UK, [7]Department of Respiratory Medicine, University Hospitals Birmingham NHS Foundation Trust, UK, [8]Department of Cardiothoracic Surgery, Sheffield Teaching Hospitals NHS Foundation Trust, UK, [9]Respiratory Medicine, Salford Royal NHS Foundation Trust, UK, [10]Leeds Teaching Hospital Trusts, UK, [11]University of Manchester, UK, [12]The Christie NHS Foundation Trust, UK, [13]Lung Cancer & Thoracic Surgery Directorate, Wythenshawe Hospital, Manchester University NHS Foundation Trust, UK, [14]Nottingham City Hospital, UK

Background: Optimal treatment of fit patients with Stage III-N2 non-small-cell lung cancer (NSCLC) requires multi-modality treatment: surgery and/or radiotherapy and systemic anti-cancer therapy. Trials in this area have struggled to recruit and quality of life (QOL) research is limited.

Aims: To explore experiences of patients, carers and multi-disciplinary team (MDT) members in relation to the PIONEER trial. Specifically, to explore:

1. Experience of the recruitment process
2. Impact of trial participation
3. Improvements and considerations for a future trial

Methods: Multi-site randomised controlled feasibility study. Patients with ‘potentially resectable’ N2 NSCLC and an MDT recommendation for multi-modality treatment were randomised to receive multi-modality treatment with or without surgery. Recruitment consultations were audio-recorded. Semi-structured interviews were conducted with patients/carers and MDT members and analysed thematically. Patients/carers completed weekly diaries.

Results: Twenty-eight patients and nine carers participated in the trial. Twelve patients, two carers, four declining patients and 20 clinicians were interviewed. Recruitment consultations of 16 patients were recorded; four of these patients declined to take part and the remainder consented. Twenty-two patients and eight carers completed diaries at least one time point, five patients completed diaries at every time point. MDT members from each of the ten recruiting sectors took part in interviews. Key themes from interviews with patients/carers included: Pre-trial experience; Carer experience of the healthcare system; Physical impact of the treatment; Impact on patient/carer QOL; Coping mechanisms; Role of the carer; Trial processes and improvements. Main themes from interviews with clinicians included: Role of the clinician; Patient factors; System issues; Decision-making; Future trials considerations.

* * *

The impact of living with advanced disease on a low income in rural and urban areas: The Unreached study

Prof Lynn Calman[1], Prof Mari Lloyd-Williams[2], Dr Naomi Richards[3], Dr Michelle Myall[1], Dr Joanne Williams[1], Dr Caroline Mogan[2], Dr Samuel Quinn[3]
[1]Southampton University, UK, [2]Liverpool John Moores University, UK, [3]University of Glasgow, UK

Background: Little attention has been paid to the lived experiences of people with advanced disease and their families who are experiencing financial insecurity and low income at the end-of-life.

Aims: The primary objective of this qualitative study is to understand the experiences of people on low incomes who are living with advanced disease (cancer and non-cancer) and those who support them in both rural and urban areas.

Methods: In this ongoing qualitative study, data collection comprises in-depth semi-structured interviews conducted with a diversity of purposively sampled participants (target n=90) recruited via national support services, third-sector organisations, and social media across three localities in the UK (North-West and North Wales, Scotland, and Southampton/Hampshire) focusing on people living with advanced disease and family carers. The interview guide is designed to explore and capture individual's lived experiences; a framework approach is being employed to analyse the data and identify key themes.

Results: Preliminary analysis of completed interviews (n=26) identify four main themes (1) high heating costs and poorly insulated homes (2) reliance on taxis owing to limited, infrequent, unreliable, and costly public transport (3) expensive home adaptions, repairs, and specialised equipment (4) increased financial precarity due to limited accessibility to statutory health services.

Despite this, strong community ties were revealed as a vital support system. Family, neighbours, and local charities provided financial aid and practical assistance; government benefits and charitable grants were essential in alleviating some financial stress. Pets offered emotional support, enhancing well-being, and access to schemes like Motability, initially improved independence. However, participants viewed income support as insufficient and application processes arduous.

Conclusion: Preliminary findings offer valuable insights into the experiences of people living with advanced disease. The completed study outcomes will be shared with key stakeholders and recommendations co-developed including a policy brief for professionals, carers, and the public.

* * *

Flash Presentations: Adolescent and young adult cancer

Mental Health at diagnosis: a barrier to research and clinical trial entry for adolescents and young adults (AYA) with cancer

Dr Lorna Fern[1], Prof Rachel Taylor[1], Prof Rachel Hough[1], Tara Searle[1], Eleanor Snowden[2]
[1]University College London Hospitals NHS Foundation Trust, UK, [2]Cynefin, UK

Background: In England, the inclusion of adolescents and young adults (AYA) in cancer trials is advocated in healthcare policy, recognising that improvement AYA outcomes have not mirrored those seen in some children's and older adult cancers. The National Health Service (NHS) five-year Long-Term Plan sets a target of 50% of AYA entering trials by 2025. Interventions to improve recruitment are lacking.

Aims: We aimed design a series of 'safe to fail' experiments, examining the experiences of AYA being offered research, and the experiences of healthcare professionals (HCP) approaching AYA about research at a large AYA Principal Treatment Centre.

Methods: We worked with Cynefin, adopting novel SenseMaker® technology combining quantitative and qualitative data with personal experiences and stories. A multidisciplinary professional group and patient group co-created a bespoke interactive survey capturing data utilising open ended, triad and dyad questions. Both groups were involved in analysis, interpretation and constraint mapping to inform the safe-to-fail experiments.

Results: Multiple datasets were analysed, including SenseMaker® surveys, workshop transcripts and outputs. Sixteen AYA, diagnosed with cancer aged 16-26 and 16 healthcare professionals (HCP) completed the SenseMaker® survey. Four themes emerged:

1. Mental health at diagnosis, a volatile constraint which can change quickly with high impact.
2. Shared decision making in the clinical space, notably discrepancies between perceptions of decision-making influence, AYA versus professionals.
3. Wider support networks including the wider multidisciplinary team and peer support.
4. Affordance landscape for HCP working with AYA, particularly the current working environment (time/pressure/post-pandemic waitlists).

Constraint mapping identified three safe-to-fail experiments around communication, education and embedding research within the wider hospital environment.

Discussion: Due to the impact of a cancer diagnosis on mental health, psychosocial interventions have potential to improve AYA recruitment. In our centre, uptake of the survey was low, therefore utilisation of the full SenseMaker® methodology was not possible.

……

Psychosocial interventions for young people after cancer treatment – a realist synthesis

Susie Aldiss[1], Prof Faith Gibson[1,2], Prof Anne-Sophie Darlington[3], Dr Sandra Easedale[4], Leila Hamrang[5], Emma Potter[4], Eliza Swinburn[5], Dr Sophie Thomas[6], Dr Sarah Lea[7]
[1]University Of Surrey, UK, [2]Great Ormond Street Hospital for Children NHS Foundation Trust, UK, [3]University of Southampton, UK, [4]The Royal Marsden Hospital NHS Foundation Trust, Sutton, UK, [5]Patient and Public Involvement, UK, [6]Nottingham University Hospitals NHS Trust, UK, [7]Anglia Ruskin University, UK

Background: In 2018, the James Lind Alliance priority setting exercise for teenagers and young adults with cancer reported the top research priority as: 'What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?' Various interventions exist to support and empower young people to manage the psychosocial consequences of cancer. What is lacking is an understanding of which interventions work and for whom they are best suited.

Aim: To undertake a realist synthesis of the literature on psychosocial interventions for young people (aged 13 to 30) after completion of treatment.

Methods: We followed realist synthesis methodology. This involved: (1) defining the review scope; (2) developing initial programme theories; (3) evidence searching; (4) selection and appraisal; (5) data extraction and synthesis; (6) refining/confirming programme theory.

We searched EMBASE, CINAHL, PubMed, Scopus and PsycINFO databases from January 2005 to January 2023. We used Covidence, a web-based systematic review tool: this supported a team approach to screening, data extraction and quality assessment.

Results: We screened 9654 studies by title and abstract, 385 were eligible for full text review. We excluded 361, leaving 24 studies. When combined, these 24 studies included 766 participants. Some studies were small, with the smallest recruiting six participants. There were four randomised controlled studies, 10 pilot/feasibility studies and 10 early qualitative and explorative studies - together indicating early development and testing of interventions, but a lack of progression to further testing.

Conclusion: Psychosocial support intervention was the focus of this review. The majority of studies in our review were small, rarely repeated and exploratory in nature. We are failing to build evidence for practice. Despite this, we are able to present programme theories, supported by empirical evidence.

* * *

"I did it to protect them": Young people, supporters and healthcare professionals experiences of triadic communication

Deborah Critoph[1], Dr Luke Smith[2], Dr Rachel Taylor[3], Dr Helen Hatcher[2], Dr Robbie Duschinsky[1], Dr Anna Spathis[1]
[1]University Of Cambridge, Cambridge, UK, [2]Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK., Cambridge, UK, [3]Department of Targeted Intervention, University College London, London, UK

Background: It is increasingly recognised that young people with cancer (AYACs) have communication needs that differ significantly from younger children and older adults. Effective communication improves health outcomes, by ensuring patient engagement, reducing distress, facilitating decision-making and increasing treatment concordance. AYACs mostly experience triadic communication, the presence of a third person in a conversation, with 87% of young people attending with a supporter. Little research has examined triadic communication, and the complex interactional dynamics in these triadic encounters are poorly understood.

Aims: As part of a large qualitative co-design study, we were seeking to understand the communication experiences of all three parties. Our aim was to investigate the impact on AYACs when a supporter is present.

Methods: Twenty-seven semi-structured interviews were undertaken, involving nine triads of a) young people b) supporters and c) professionals. Three focus groups with AYACs (n=4), supporters (n=3) and professionals (n=6), were conducted virtually. Interviews and focus groups were digitally recorded and analysed thematically.

Results: Triadic communication is complex. Five key analytical themes were identified:

1. Young people frequently become disengaged from the communication triad for multiple reasons, including mutual protectionism.
2. Non-parental supporters are often important to the young person but are sidelined in triadic communication. Most supporters are parents.
3. Healthcare professionals perceive multi-level threat that collectively hinder effective triadic communication.
4. Triadic communication is a dynamic process that needs to continually adapt to change and uncertainty.
5. Tension and conflict are inherent to triadic communication. Differing perspectives and threat responses led to pervasive tension.

Conclusion: Adolescents and young adults with cancer experience considerable unmet needs in relation to triadic communication. Professionals must enable young people to communicate in the presence of a supporter, including facilitating ‘time alone’. Training professionals in triadic communication is critically important and needs to be developed as a priority.

……

Oral Presentations: Supportive care needs in understudied cancer groups

Coping with the Unknown: Illness Uncertainty in Patients Receiving Radiotherapy and Proton Beam Therapy

Danielle Fairweather[1], Prof Rachel Taylor[1,2], Rita Simoes[1]
[1]University College London Hospitals NHS Foundation Trust, London, UK, [2]University College London, London, UK

Background: Over 40% of patients undergoing radiotherapy or Proton Beam Therapy (PBT) experience psychological distress, with illness uncertainty being a key contributor. Increased uncertainty negatively impacts psychological adjustment and quality of life. Identifying common sources of uncertainty and patient coping strategies can help clinicians better address patients' emotional and physical needs.

Aims: This study aimed to apply Mishel's theory of uncertainty to interview data collected from a sample of patients who had received radiotherapy or proton beam therapy.

Methods: A qualitative study using semi-structured interviews was conducted with a purposive sample of patients, reflecting the main indications for radiotherapy and PBT. Semi-structured interviews were conducted between August 2023 and January 2024 either in person, virtually or by telephone. The interviews were digitally recorded and transcribed using AI transcription software (Otter AI). Transcripts were analysed using Framework Analysis, then interpreted deductively against Mishel's theory of uncertainty.
Results: In total, 20 patients were interviewed. All patients experienced feelings of uncertainty before, during, and after treatment. Many sources of uncertainty were reported, such as cancer unpredictability, treatment outcomes, lack of understanding of the treatment process, symptom events, radiotherapy machine breakdowns, and waiting times. These sources of uncertainty negatively affected patients' mental well-being. Coping strategies included information-seeking and emotional support (active) from their healthcare teams, as well as emotional disengagement (avoidant).

Conclusions: Receiving radiotherapy and PBT comes with unique challenges, but uncertainty is universally shared amongst cancer patients. Further research is needed to address uncertainty and improve patient coping and quality of life during and after treatment. Incorporating uncertainty into existing psychological prehabilitation models, and adapting this to radiotherapy and PBT pathways, could be a way of supporting this.

……

'A Waiting game' – Interpretations of psychosocial experiences and support needs of a new head and neck cancer management pathway

Sara Matthews[1], Prof Jo Brett[1], Prof Eila Watson[1], Doctor Pras Ramluggun[1]
[1]Oxford Brookes University, Oxford, UK

Background: Over the lifetime of BPOS the incidence of oropharyngeal cancer, a type of head and neck cancer, has increased dramatically, attributed to the human papillomavirus (HPV). Often occurring in middle-age, it typically has a good prognosis, but treatment can leave severe side effects. A new management pathway introduced in 2018 aims to reduce morbidity in survivorship. A response assessment scan, 12-16 weeks after (chemo)radiotherapy, now determines the need for surgery, previously planned for all.

Aims: To understand psychosocial experiences and propose support for patients and informal caregivers on this pathway.

Method: A qualitative approach enabled exploration, informed by past research, of early recovery. 25 semi-structured interviews were coded using the Framework Method and thematically analysed. Findings were matched to theoretically based interventions, and proposals for support developed during consultation with patients, caregivers and clinicians.

Results: Five patient themes revealed a ‘Rollercoaster of early recovery’ and ‘Disrupted self-identity’, informing ‘Expectancy of recovery’, ‘Coping with disruption and uncertainty’ and ‘Accessing support’; impacting illness interpretations for self-management. An overarching theme of an ‘Emotional Journey’ depicted caregivers’ experiences, with sub-themes conveying the role and its impact. ‘Expectancy development’, a fourth sub-theme, incorporated similar anticipation and uncertainty as for patients from the ‘Waiting game’; an interpretation of the new pathway. Caregivers also described ‘Coping’ and ‘Support in the role’. Unmet needs and moderators of uncertainty, including personal characteristics, preparation for caregiving and perceived availability of support, were identified. Recommendations for supportive interventions, include internet-based access to peers’ experiences to help shape expectations of recovery.

Conclusion: Uncertainty whilst waiting for treatment outcome on the new pathway can impact self-management and help-seeking. Proposals for tailored support aim to meet identified needs, including greater preparedness for the ‘Waiting game’ during early recovery, for the impact of treatment and necessary adjustments in life, and for the caregiving role.

* * *

Disparities in breast cancer care among Taiwanese women with mental health disorders

Yueh-Hsin Wang[1], Prof Ajay Aggarwal[1,2], Prof Elizabeth Davies[1]
[1]Centre for Cancer Society & Public Health, Comprehensive Cancer Centre, Faculty of Life Sciences & Medicine, King's College London, UK, [2]Department of Health Services Research and Policy, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, UK

Background: International studies reveal disparities in breast cancer screening participation and treatment for women with pre-existing mental health disorders (PMHD). No study has yet investigated screening uptake and treatment nationally for East Asian women with and without these disorders.

Aim: We conducted two cohort studies to compare breast cancer screening uptake and treatment between Taiwanese women with and without PMHD.

Methods: Mental health disorders were identified based on women's medical records from three years before the study period or breast cancer diagnosis. In the first cohort, women eligible for breast cancer screening in 2013 were observed for their participation in screening from 2013 - 2016. Propensity score matching was used to minimise potential confounding factors between women with and without disorders. In the second cohort, women diagnosed with breast cancer at stages I-III from 2010 - 2016 and who underwent breast cancer surgery within 12 months of diagnosis were compared for the type of surgery they received.

Results: Propensity score matching was performed for 3,461,655 women, and then 621,198 women (with PMHD: 103,533) were used to compare screening attendance. No significant differences in screening attendance between the two groups ($p > .05$) were observed. However, among 56,874 women with stages I-III breast cancer, those with PMHD were less likely to undergo breast-conserving surgery than mastectomy compared to those without (OR = 0.81, 95% CI = 0.68-0.97).

Conclusion: Taiwanese women with PMHD do not differ in their participation in breast cancer screening compared to those without. This may be due to an environment full of screening advertisements. However, like women in the US, Denmark, and Japan, Taiwanese women with PMHD are less likely to undergo guideline-recommended surgical treatment. These findings may also provide insights into the situation in the UK, which has a similar national health insurance system.

* * *

OPTIMISTIC – Optimising the care and support for people with inoperable pancreatic cancer and their family carers

Hilary Brown[1], Prof Eila Watson[1], Prof Annie Topping[2,3], **Dr Lucy Mcgeagh**[1]
[1]Oxford Brookes University, Oxford, England, UK, [2]University of Birmingham, Birmingham, England, UK, [3]University Hospitals Birmingham, NHS Foundation Trust, Birmingham, England, UK

Background: Evidence suggests that people affected by inoperable pancreatic cancer have a range of unmet needs and the care of those with the disease is inconsistent.

Aims: This research examined the supportive care needs of people with inoperable pancreatic and their carers over time, and the challenges faced by HCPs in providing optimal supportive care.

Methods: A qualitative, intrinsic case study interview design was used. In total, 60 semi-structured interviews involving 13 patients, 12 family carers (FCs) and 24 healthcare professionals were conducted. Where possible, patients and FCs were interviewed more than once. Fitch's Supportive Cancer Care Framework was used as a theoretical framework and transcribed data were analysed using the Framework Approach.

Results: Care co-ordination was often inadequate, particularly outside of the acute sector, while experiences of care were often adversely affected by poor communication. Unmet information needs were significant at all points along the cancer trajectory. Unmet physical needs associated with the management of pancreatic enzyme Insufficiency (PEI) and the side effects of chemotherapy were most significant, alongside unmet psychological and emotional needs in response to diagnosis, prognosis, and the rapid progression of the disease.
Recommendations to address these shortfalls include timely access to Cancer Nurse Specialist support, the introduction of fast-track pathways to supportive care services, the early introduction of community palliative care services and Advanced Care Planning, the promotion of resources and support to patients and FCs and sources of advice for GPs, and a focus on improving communication.

Conclusions: Focusing on discrete interventions or services to address specific needs risks marginalizing the fundamentals of patient experience. The adaption of Fitch's Framework to include a construct of 'how' care is delivered would underscore that optimal supportive care incorporates the entirety of the care experience.

* * *

Co-designing a web-based intervention (RESTORE) to support self-management of cancer-related fatigue in people living with a brain tumour

Dr Rachel Campbell[1], Prof Joanne M Shaw[1], Hannah Banks[1], Thomas Carlick[1], Dr Mona M Faris[1], Dr Megan S Jeon[1], Dianne Legge[2], Prof Claire Foster[3], Robyn Leonard[4], Prof Raymond J Chan[5], Prof Meera R Agar[6], Annie Miller[1], Prof Haryana M Dhillon[1]
[1]Psycho-Oncology Cooperative Research Group, School of Psychology, Faculty of Science, The University of Sydney, Australia, [2]Curtin School of Nursing, Curtin Health Innovation Research Institute, Faculty of Health Sciences, Curtin University, Australia, [3]Centre for Psychosocial Research in Cancer (CentRIC), School of Health Sciences, University of Southampton, The UK, [4]Brain Cancer Collective, NHMRC Clinical Trials Centre, University of Sydney, Australia, [5]Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Australia, [6]Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT), Faculty of Health, University of Technology Sydney, Australia

Background: Cancer-related fatigue (CRF) is a debilitating symptom commonly reported by people with a brain tumour (BT). RESTORE is an online intervention that demonstrated preliminary efficacy in enhancing self-efficacy to self-manage CRF following primary cancer treatment. However, previous evaluations of RESTORE did not include people with BT.

Aim: Given the unique functional deficits experienced by people with BT, we aimed to explore the appropriateness of RESTORE to support self-management of fatigue in this population, and identify modifications required.

Methods: We conducted semi-structured interviews with people with BT, their caregivers, and healthcare professionals (HCPs) who treat them. Before the interview, participants reviewed a video summarising the intervention components and accessed the intervention. Interviews explored the appropriateness of RESTORE for this population, and suggested modifications to improve relevance and suitability. Interviews were transcribed, coded and analysed thematically using interpretive description to devise recommendations.
Results: A total of 40 participants were interviewed (24 people with BT, 5 caregivers, 11 HCPs). We identified four themes: 1) feedback on content; 2) feedback on format; 3) feedback on use; and, 4) barriers to engagement.
These themes were linked by an overarching need for flexible and responsive tailoring to the unique needs of people with BT. We derived 32 recommended modifications from feedback to optimise RESTORE for this population.

Conclusion: Our results suggest a BT-specific version of RESTORE is desirable and would be acceptable to address fatigue in this population. Adaptations needed include greater flexibility and tailoring of content and format for effective use among people with BT. Based on these recommendations, we are developing a BT-specific version of RESTORE; the prototype will be presented at the conference. Barriers to engagement including digital access and literacy, caregiver burden, and awareness of the resource, will need to be addressed in the implementation of this BT-specific version of RESTORE.

* * *

Finding My Way UK: A replication randomised controlled trial of online psychosocial support for cancer survivors

Prof Nick Hulbert-Williams[1], Monica Leslie[2], Dr Lee Hulbert-Williams[1], Dr Andrea Piovesan[1], Dr Tim Cartwright[1], Dr Rosina Pendrous[3], Dr Mollie Price[4], Laura Davies[1], Prof Bogda Koczwara[5,6], Dr Peter Hall[7], Richard Jackson[8], Prof Neil Coulson[9], Prof Eila Watson[10], Prof Laura Ashley[4], Ms Sue Millington[11], The Finding My Way UK Steering Group[11], Prof Lisa Beatty[5]
[1]Edge Hill University, Ormskirk, UK, [2]Macquarie University, , Australia, [3]University of Birmingham, , UK, [4]Leeds Beckett University, UK, [5]Flinders University, Australia, [6]Southern Adelaide Local Health Network, Australia, [7]Edinburgh Cancer Research Centre, UK, [8]Liverpool Clinical Trials Centre, UK, [9]University of Nottingham, UK, [10]Oxford Brookes University, UK, [11]No affiliation, N/A

Background: Finding My Way is a self-directed, online programme to support psychosocial wellbeing in cancer survivors. Findings from previous Australian clinical trials report positive outcomes on distress and healthcare cost.

Aims: Whilst maintaining the overall structure and therapeutic framework, we adapted Finding My Way for the UK healthcare setting. After user-testing, we undertook a replication trial to test effects on cancer-specific distress, mental health outcomes and healthcare utilisation, including embedded qualitative interviews.

Methods: 299 curatively-treated adult cancer survivors (Age M=60 years; 59% female) completed self-report questionnaires assessing socio-demographic characteristics, trial outcomes, and postulated moderators/mediators. Participants were randomised 1:1 to FMW-UK or control group, repeating the same questionnaires at mid-treatment, post-treatment, and at three- and six-month follow-up.

Results: 62% of patients screened were eligible to take part, and fewer than 7% withdrew consent during the trial. Intervention engagement decreased over time: on average, 4 out of 7 modules were completed. Distress and mental health outcomes improved, and quality of life domains were either maintained or improved for all participants, but there were no significant between-group differences at follow-up.

Intervention effects were more pronounced in those with elevated depression, anxiety and stress at baseline, though statistical tests were underpowered to detect significance. Analysis of healthcare utilisation data indicates some potentially important economic differences between groups: though non-significant, intervention group participants were financially better off and reported healthcare use which implies a greater level of self-management and use of more symptom-appropriate services.

Qualitative interview data indicates acceptability and subjectively-reported intervention benefits that were not recorded in statistical analysis.

Conclusion: Recruitment willingness indicates a need for accessing psychosocial support, and both engagement and qualitative interview data demonstrates acceptability. Low baseline distress findings may indicate a mismatch between participant expectations for engaging with digital health interventions, and trial outcomes assessed.

* * *

CAN-EMPOWER: Development and testing of an online intervention to build confidence in self-managing the psychological implications of cancer diagnosis and treatment

Dr David Wright[1], Dr Dan Aze[1], Dr Sebastien Pollet[1], Dr Jo Williams[1], Prof Claire Foster[1], Prof Lynn Calman[1]
[1]University of Southampton, Hampshire

Background: People living with cancer can experience psychological problems related to their diagnosis and treatment, including anxiety and fear. Left unsupported, these may persist for years after completion of treatment. People may lack the confidence to self-manage psychological difficulties, limiting health and wellbeing recovery. Online resources are effective in supporting self-management, but no evidence-based online resources exist to build confidence to self-manage the psychological implications of cancer.

Aim: To develop a freely available, evidence-based online resource to enhance confidence to self-manage psychological problems associated with cancer.

Methods: The project adopted the Personal Based Approach and was informed by Self-Efficacy Theory. It involved the following:

1. Systematic Literature Review of interventions and barriers / facilitators to use.
2. Web Review of cancer-related digital / online resources.
3. National cohort data analysis on depression and anxiety prevalence and changes over time.
4. Five Nominal Group Technique stakeholder groups with 25 people living with cancer, befrienders and healthcare professionals.
5. Twenty-five 'Think aloud' interviews.
6. Seventeen qualitative interviews after home-testing.

Results: CAN-EMPOWER (http://can-empower.org.uk) is a free online resource co-created with people with lived experience of cancer and healthcare professionals. It is structured on areas prioritised through the stakeholder groups: Normalisation (understanding implications of cancer diagnosis and treatment); General Coping Techniques (e.g. healthy lifestyles, problem solving, goal setting); Specific areas of concern (worry, anxiety, fear and anger; 'feelings about yourself'; managing the impact of cancer; talking to others; impact on the family). Home testing revealed the resource improved understanding about the psychological implications of cancer, built confidence to address these difficulties and provided appropriate links and practical techniques to manage concerns.

Conclusion: CAN-EMPOWER is an acceptable, evidence-based resource that builds confidence to self-manage the psychological implications of cancer. It provides information and techniques that can be used with the guidance of a clinical team.

* * *

Oral Presentations: Understanding the impact on families and caregivers

Roles and responsibilities of informal caregivers in pancreatic cancer: preliminary findings from a qualitative study

Jennifer Deane[1], Rosalind Carlisle[2], Prof Catherine Exley[1], Prof Eila Watson[3], Dr Sian Russell[1], Dr Adam Biran[1], Prof Sanjay Pandanaboyana[2], Prof Linda Sharp[1]
[1]PHSI, Newcastle University, UK, [2]Newcastle Hospitals NHS Foundation Trust, UK, [3]Oxford School of Nursing and Midwifery, Oxford Brookes, UK

Background: Patients with pancreatic cancer experience significant symptom burden and unmet needs, often relying on informal carers (family or friends) for support. Carers often undertake new roles and responsibilities, and this can have significant emotional, physical, and social impact on their lives increasing carer burden and reducing quality-of-life. However, limited data exist on experiences of informal caregiving in pancreatic cancer.

Aims: This study aimed to explore the roles and responsibilities undertaken by carers and how this impacted their experience.

Methods: Carers were recruited through 6 NHS Trusts to take part in a longitudinal questionnaire study and were then asked if they would be willing to take part in an additional in-depth semi-structured interview. Additional participants were recruited through Pancreatic Cancer UK. Interviews were conducted via video or telephone. Recruitment continued until the study reached theoretical sufficiency. Thematic analysis was then conducted on the data.

Results: 26 Interviews were conducted (18 female, 8 male; aged 27–78 years, mean duration 68 minutes).

Preliminary analysis has developed six Themes relating to roles and responsibilities carers take on; (1) System Navigator – this role includes making appointments, communicating with healthcare professionals, and chasing referrals; (2) Researcher Nurse – looking for alternative treatments, understanding medication; (3) Home tasks – undertaking tasks needed to keep the home running; (4) Emotional and Social Support – providing support for patient and often for wider family network; and (5) End of Life Care – providing support when the patient is dying.
All of this is seen within the theme of Changing Role – for example the change from daughter to nurse, and how this change impacts their relationships (positive and negative).

Conclusion: Understanding the roles and responsibilities carers undertake is essential for developing support that reduces their burden and improves quality-of-life for this group.

* * *

Supporting parents living with cancer: A new psychoeducational intervention

Dr Caroline Leek[1]
[1]Fruit Fly Collective

Background: Parents diagnosed with cancer struggle with navigating family life. They report feeling isolated, anxious, worry they are damaging their children's lives, and feel wholly unsupported.

Aims: To develop a psychoeducational intervention that 1) improves the mental wellbeing of parents experiencing cancer, and their children, 2) provides therapeutic tools and skills that empower parents to support their children.

Methods: 70 parents participated in the Parenting with Cancer coaching programme. Inclusion criteria: responsible for children under the age of 18 years old; living with cancer or had previously experienced cancer, or co-parenting with a parent diagnosed with cancer. The online programme was eight weeks with each session lasting 90 mins. Sessions were either in the evening or in the morning. Each participant completed a pre and post questionnaire containing three validated scales: The Short Warwick-Edinburgh Mental Wellbeing Scale, The Parental Stress Scale and The Brief Parental Efficacy Scale.

Results: Data from 51 parents were analysed using paired t-tests to measure the change in participants before and after the coaching. We found that parents who participated in the Parenting with Cancer Coaching Programme were significantly more satisfied and happier in their role as being a parent, and their mental well-being had significantly improved. They also felt less overwhelmed with the responsibility of being a parent, less stressed with their children and their children's behaviour.

Parents had significantly higher levels of parental self-efficacy and worried less about not doing enough for their children. They felt closer to their children, enjoyed spending more time with them, and felt they had more time and flexibility in their lives.

Conclusion: Our results show that the Parenting with Cancer coaching programme is a successful intervention that significantly supports the mental wellbeing of cancer patients who are parents, and their children.

* * *

'What are we going to say to the kids?' Experiences of family support when a parent of dependent children has cancer that cannot be cured: insights from a service evaluation.

Dr Jane Cockle-Hearne[1], **Dr Katie Sutton**[1], Katherine Cooper[1], Prof Emma Ream[1]
[1]University of Surrey, School of Health Sciences, Guildford, UK

Background: Despite evidence indicating the importance of supporting families when a parent with dependent children has cancer that cannot be cured, there is inconsistency in the provision of pre-bereavement care across health care services. To meet this gap, the Family Support Service, delivered through a UK cancer charity, offers free support provided by BACP-registered counsellors, social workers and healthcare professionals, plus free support resources. Understanding how parents have responded to this Service is crucial for its longer-term development and for wider provision opportunities.

Aim: To explore users' pre-bereavement needs and experiences, examine how their needs have been met by the Service, and identify ways in which the model of support can be developed to continue to meet parents' and families' needs.

Methods: 20 pre-bereaved and bereaved parents who had used the Family Support Service took part in semi-structured interviews as part of a mixed methods, convergent, parallel evaluation of the Service. Interviews were conducted on Microsoft Teams, recorded, transcribed and analysed with a Framework Approach.

Results: Parents' perspectives on support varied throughout the impact of diagnosis, navigating pre-bereavement, bereavement and ongoing grief. Challenges arose because of parents' ever-changing roles and the complicated, highly individual support needs of children, in particular teenagers. The flexible support received through the service was extremely valued, as was, the focus provided for teenagers, the validating approach for parents supporting their children, and the opportunity to spend time and discuss the 'unsayable', with others in group sessions.

Conclusions: Evaluation confirmed the person-centred approach delivered by the Service and highlighted its relevance and apposite delivery across the treatment and palliative care pathway for parents with incurable cancer who have dependent children. Development opportunities included: early pre-bereavement support, further access to online talks and support groups (particularly for teenagers), and the continuation of support into early bereavement.

Exploring the Supportive Care Needs of Families Affected by Pancreatic Cancer in Northern Ireland: A Mixed-Methods Study Protocol

Tara Anderson[1], Dr Gillian Prue[1], Dr Lisa Graham-Wisener[1], Dr Gary Mitchell[1]
[1]Queen's University Belfast, Northern Ireland

Background: Pancreatic cancer is an aggressive disease with most cases diagnosed at an advanced stage resulting in low survival rates. Family members often take on a role of supporting patients' needs. Families tend to be unprepared for this and experience high levels of unmet needs and substantial impacts to their own wellbeing, heightened by the rapid deterioration and short life expectancy associated with pancreatic cancer. As Northern Ireland has one of the lowest 5-year survival rates for pancreatic cancer in Europe, family members may be at increased risk of unmet supportive care needs.

Aim: The proposed study aims to explore the supportive care needs and psychosocial impact of pancreatic cancer on families, and the role of support services in supporting these families.

Methods: A sequential explanatory mixed methods design will be utilised. Data collection will consist of three phases: 1) Survey of affected family members to explore their supportive care needs and psychological wellbeing; 2) Semi-structured interviews exploring the lived experiences of family members, their psychosocial adjustment, and perceptions of support services; 3) Focus groups with support services providers to explore their experiences in supporting families. Regression analyses will be utilised for survey data to explore associations between participant characteristics and areas of unmet need, and between areas of unmet need and psychological outcomes. Interviews and focus group data will be analysed using reflexive thematic analysis.

Discussion: By combining quantitative and qualitative approaches, this research aims to provide a comprehensive understanding of the challenges and opportunities in supporting families affected by pancreatic cancer, ultimately enhancing their quality of life during and after their cancer journey. This research will foster collaboration between healthcare providers, statutory services, and charities in Northern Ireland. The findings may help to inform the enhancement of support programs, tailored to meet the specific needs of affected families.

……

Evaluation of the preliminary effectiveness, accessibility and experience of a six-week mindfulness skills course for patients with cancer.

Dr Jennie Baxter[1], Dr Yasemin Dandil[1], Sara Lister[1], **Subbanke Vanniyasingam**[1], Dr Justin Grayer[1]
[1]Royal Marsden NHS Foundation Trust, UK

Background: Mindfulness-based interventions are receiving growing attention within cancer care, helping patients cope with cancer-related distress and physical pain.

Aims: This service evaluation explores preliminary effectiveness, accessibility, and experience of a six-week mindfulness course specifically designed for patients with cancer in a specialist psycho-oncology service.

Method: A mixed-methods design was employed. Patients (n = 98) attended the course completing pre and post self-report measures for mindfulness, psychological distress and physical pain. Accessibility was explored to identify barriers to attendance and under-represented patient characteristics. Patient feedback on the experience of attending the course was elicited, with free-text responses and personal perceived meaningful outcomes analysed using a framework analysis method.

Results: Self-reported levels of mindfulness increased at the end of the course and self-reported psychological distress, and physical pain intensity decreased. Most patients (59.3%) engaged in home practice 2-3 times a week during the mindfulness course, and more than half (58.8%) strongly agreed that they intended to continue. The course was generally well received with several prominent themes, including increased autopilot awareness, increased mindfulness in everyday life and perceived usefulness of guided practice. A number of positive meaningful outcomes were named including skills acquisition and self-compassion, Patients reported being in a group fostered a sense of community and encouraged adherence to home practice during the course. Online delivery supported physical and emotional comfort and aided access. In person attendees noted difficulties (i.e. size and location of the venue). There was no significant difference in cancer type, ethnicity, age, or gender between those who attended, dropped out or declined.

Conclusions: Preliminary support for effectiveness, accessibility and experience of the six-week mindfulness skills course was found. Changes to future delivery including post course drop-in sessions to support continued practice are indicated. Limitations of this service evaluation and suggestions for future research are discussed.

Assessing the impact of timely diagnosis on psychological outcomes and quality of life for cancer patients: a scoping review

Laura Boswell[1], Dr Jenny Harris[1], Dr Richard Green[1], Prof Jo Armes[1], Dr Georgia Black[2], Prof Katriina Whitaker[1]
[1]The University of Surrey, Guildford, UK, [2]Queen Mary University of London, UK

Background: Timely diagnosis and cancer treatment are crucial for improving patients' outcomes and prognosis. While the impact of prolonged diagnostic/treatment intervals on survival is well-documented, the psychological effects of timely cancer diagnosis are less understood. Evaluating outcomes beyond survival is crucial due to the increasing number of cancer patients and the rising survival rates owing to advancements in treatments and early detection.

Aim: We reviewed the literature on timely cancer diagnosis and its impact on psychological outcomes and quality of life (QoL) in cancer patients, focusing on a) types of psychological and QoL outcomes studied, b) methods used to assess these outcomes, c) conceptualisation/measurement of timely diagnosis, and d) evidence linking timely diagnosis with psychological outcomes and/or QoL in cancer patients.

Methods: Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews, we conducted a scoping review to map existing literature. After removing duplicates, 4,194 studies were screened. A quality appraisal was performed using a validated appraisal tool and cancer-specific quality reporting criteria.

Results: Six studies were identified. Four studies employed cross-sectional surveys, while one each used qualitative and mixed-method designs. Quantitative evidence indicates that timely diagnosis correlates with improved psychological outcomes and quality of life. Qualitative and mixed-method evidence suggested a positive impact on psychological outcomes without focusing on it. Definitions of timely diagnosis varied, including diagnostic intervals from electronic health records, the number of pre-referral consultations with general practitioners, and self-reported participant accounts. No study met all quality appraisal criteria, with dates of events leading up to diagnosis being the least reported (0/6 studies).

Conclusion: Preliminary evidence suggests timely diagnosis may influence psychological outcomes and quality of life in cancer patients, but methodological heterogeneity limits the findings' generalisability. Further research is needed to investigate patients' lived experiences during the adjustment process.

……

Evaluating the Fear of Cancer Recurrence Inventory: Psychometric insights from people with sarcoma

Dr Tim Cartwright[1], Dr Lee Hulbert-Williams, Prof Rachel Taylor, Dr Lesley Storey, Prof Nick Hulbert-Williams
[1]Edge Hill University, Ormskirk, UK

Background: The Fear of Cancer Recurrence Inventory (FCRI) is a widely used 42-item measure assessing seven dimensions of fear of cancer recurrence (FCR). While its psychometric properties have been established in various populations, its validity among individuals with sarcoma remains underexplored. Sarcoma survivors face unique psychological challenges, necessitating an evaluation of the FCRI's applicability in this group.

Aims: This study aimed to cross-validate the FCRI in a sample of individuals with sarcoma and evaluate its concurrent, convergent, incremental, and construct validity.

Methods: The study included 229 UK participants (M age = 52.45) diagnosed with sarcoma. Participants completed the FCRI, an additional FCR measure, and a set of psychological outcome measures. Cronbach's alphas and correlations with the other measure of FCR and psychological outcomes were computed. Construct validity was evaluated through confirmatory factor analysis (CFA), and the measure was further explored using Item Response Theory.

Results: The FCRI demonstrated acceptable to good internal consistency and strong convergent validity. Concurrent validity was moderate, while incremental validity was particularly robust for the functional impairments and insight subscales in predicting psychological outcomes. However, construct validity testing revealed some challenges: four items had poor factor loadings, three exhibited cross-loadings, and the coping strategies subscale displayed multidimensionality, resulting in suboptimal model fit. Modifications addressing Likert response anchors, cultural differences, and conceptual overlaps improved model fit to acceptable levels (CFI = .922, TLI = .912, RMSEA = .059, SRMR = .059).

Conclusion: The FCRI demonstrates strong psychometric properties overall but requires refinements to improve construct clarity and applicability, particularly for sarcoma patients. Recommendations include revising specific items to address conceptual and methodological concerns and improving its adaptability for diverse cancer populations. Despite limitations, the data support the continued use of the FCRI in psychosocial oncology research and practice.

……

Understanding the Lived Experiences of People Diagnosed with Pancreatic Cancer in Northern Ireland: A Study Protocol for a Grounded Theory Approach

Lana Cook[1], Dr Gary Mitchell[1], Dr Gillian Prue[1]
[1]School of Nursing and Midwifery, Queen's University Belfast, Belfast, Northern Ireland

Background: Mortality rates for pancreatic cancer remain high, with some of the worst five-year, global survival rates experienced in Northern Ireland. Literature on patients' experiences is scarce, so their needs are poorly understood, but they experience high symptom burden and worse psychological quality of life when compared to people with other cancers. There are relatively few publications exploring people's experiences of pancreatic cancer in general and researchers have highlighted the need for more qualitative research with this population.

Aims: This study aims to explore the experiences of people diagnosed with pancreatic cancer in Northern Ireland and develop a theory to explain the process of their journeys from (pre)diagnosis to survivorship or to end of life.

Methods: This study will adopt a QUAL-qual, simultaneous, mixed-method design. The core method is a Glaserian grounded theory study design, supplemented by an optional Photovoice/participatory photography method. It will comprise four phases: 1) a systematic review of literature on the psychosocial aspects of pancreatic cancer journeys; 2) in-person interviews with people diagnosed with pancreatic cancer; 3) in-person interviews with their care partners; and 4) focus groups with professionals and other stakeholders with insight into these experiences. Theoretical sampling principles and constant comparative analysis will guide recruitment, data collection, and analysis until a mature theory has developed.

Results: Data collection beginning January 2025.

Conclusion: Establishing holistic, in-depth understanding of people's pancreatic cancer journeys and creating a robust theory that captures this will enable us to better understand and anticipate people's needs. This theory can inform our priorities for future care and service provision, policy, and research. For instance, it may contribute to the development of appropriate support interventions that assist people to maintain the best possible quality of life for as long as possible, whether during a short-term, terminal illness; treatment journey; or long-term symptom management.

……

Setting up a systemic family therapy pathway in a remote psycho-oncology service

Dr Lisa Dvorjetz[1], **Maisie Cropley**[1]
[1]East Midlands Cancer Alliance Centre for Psychosocial Health

The National Institute for Clinical Excellence emphasises that people with cancer, and their families, should have access to psychological and emotional support; however, psychology services that offer couples or family therapy are sparse. In a recent Macmillan pan-London mapping exercise of psycho-oncology services, 23 NHS Trusts offered 97 qualified posts including psychologists, psychotherapists, CBT therapists, art therapists, counsellors, nurse counsellors and family therapists. Of those 97 posts, only 3 were dedicated family therapist posts. Therapists from other backgrounds do offer systemic work but only a small fraction of the work is with families and couples. There is little to no data for other nationwide psycho-oncology services. The aim of setting up a systemic family pathway in the East Midlands Cancer Alliance Centre for Psychosocial Health (EMCA-CPH) is to provide dedicated couples and family therapy sessions to support patients with cancer-specific issues. This is a remote service covering the five East Midland counties offering up to 12 free therapy sessions. Since commencing the pathway in August 2024, 15 out of 73 referrals (20.5%) were for couples or family work. Referral issues have included how cancer has impacted family dynamics, changes in family roles, changes in intimacy, communication difficulties, working with different cancer narratives and exploring death/dying within the family context. We aim to explore the effectiveness of the service through quantitative (PHQ-9, GAD-7 and SCORE-15) and qualitative feedback. Although in its early stages, the pathway is already providing psychological support to the cancer patient, and their system, which is a crucial step in oncology healthcare because cancer negatively impacts family relationships and the individuals' wellbeing.

……

Breast cancer patients with a pre-existing mental illness are less likely to receive guideline-recommended cancer treatment: a systematic review and meta-analysis

Katie Elliott[1]
[1]Newcastle University, UK

Breast cancer is the most commonly diagnosed cancer worldwide, with early detection and advanced treatments contributing to declining mortality rates. However, managing comorbid conditions, particularly mental illness, presents significant challenges for cancer treatment. This study systematically reviews and meta-analyses the impact of having a pre-existing mental illness on breast cancer treatment utilisation, focusing on specific treatments and comparing different mental illnesses. MEDLINE, EMBASE, CINAHL, and APA PsycInfo databases were searched. After screening, fifteen studies were identified as meeting the inclusion criteria. The included studies were predominantly from high-income countries, and compared breast cancer treatment in patients with and without pre-existing mental illnesses including anxiety, mood disorders, schizophrenia and psychotic disorders, and neurodevelopmental disorders. Meta-analysis revealed that patients with mental illnesses were significantly less likely to receive guideline-recommended treatments (OR = 0.78, 95% CI 0.72-0.83, N = 5), chemotherapy (OR = 0.56, 95% CI 0.34-0.78, N = 6), or radiotherapy (OR = 0.79, 95% CI 0.66-0.93, N = 5). They were also significantly more likely to undergo mastectomy instead of breast-conserving surgery (OR = 1.38, 95% CI 1.24-1.52, N = 4). Findings were consistent across different mental illnesses. This review highlights the need for targeted interventions to improve healthcare access and address provider biases, promoting better integration of mental health and oncology care.

Psychosocial outcomes associated with specialist care for adolescents and young adults with cancer

Dr Lorna Fern[1], Dr Elysse Bautista-Gonzalez[1], Prof Julie Barber[2], Prof Richard Feltbower[3], Prof Cecilia Vindrola Padros[2], Prof Rachel Taylor[1,2], On behalf of the BRIGHTLIGHT_2021 Study Group[1]
[1]University College London Hospitals NHS Foundation Trust, UK, [2]University College London, UK, [3]University of Leeds, UK

Background: Healthcare policy in England recognises adolescents and young adults (AYA: 16-24 at diagnosis) as having unique psychosocial needs. Psychosocial care is delivered alongside standard cancer care in the 13 specialist Principal Treatment Centres (PTCs). The PTCs deliver ‘joint-care’ with designated hospitals (DH). Our previous study completed in 2019 suggested AYA receiving ‘joint care’ experienced poorer outcomes compared to those receiving care in one hospital.

Aims: We examined whether clinically significant differences exist in patient-reported outcomes for AYA receiving ‘joint care’ compared to all (all-AYA-PTC) or none of their care (no-AYA-care).

Methods: Patients were identified via the AYA multidisciplinary team across all 13 PTCs in England between September 2013-December 2022. Data was collected by a self-report survey which captured quality of life (QoL), health status, social support, illness perception and mental health at 6-months post-diagnosis.

Results: 240/1009 (25.8%) participants returned surveys. Overall, group mean QoL scores were low (mean 59, standard deviation:20.13). Patients were categorised into all-AYA-care (n=66), Joint-care (n=89), and no-TYA-care (n=85). After adjustment for confounding factors, no significant differences existed in QoL between categories of care. The adjusted mean difference for patients receiving all-TYA-care was -2.28 units versus no-TYA=care (95% confidence interval, CI: -8.85 to 4.29) and 4.35 units compared to those receiving joint-TYA-care (CI: -10.34 to 1.63). There were no significant differences in social support, anxiety and depression, or illness perception between categories. Patients receiving all-TYA-care had lower E5QD index scores compared to the no-TYA-care category.

Conclusions: Patient-reported outcomes were similar across the three categories of care. We surmised this may be related to improvements in coordinated care over the last decade with the evolution of AYA networks. This was supported by qualitative work conducted alongside collection of AYA reported PROMS data.

……

Strategies for implementation of Patient Decision Aids for genetic testing and risk management into mainstream healthcare settings

Dr Rebecca Foster[1], Kelly Kohut[2], Lesley Turner[3], Dr Gillian Crawford[4], Dr Lucy Side[4], Dr Jackie Chandler[5], Prof Diana Eccles[1], Prof Claire Foster[1]
[1]University Of Southampton, UK, [2]St. George's University Hospitals NHS Foundation Trust, UK, [3]Patient representative, UK, [4]Wessex Clinical Genetics Service, University Hospital Southampton NHS Foundation Trust, UK, [5]Health Innovation Wessex, UK

Background: Genetic testing allows identification of pathogenic variants that drive tumour development and, if present in the germline, increase future cancer risk. Results are important to guide cancer treatment, surveillance and risk management. However, deciding whether to undergo testing and how to act on test results can be difficult for patients as they consider the potentially far-reaching consequences for themselves and their families.

Aims: Lynch Choices (LC) and Breast Cancer Choices (BCC) are web-based patient decision aids (PtDAs), co-designed with patients and expert partners, to assist patient decision-making regarding genetic testing and risk management. Two separate evaluations of BCC and LC are ongoing. Our aim is to focus on evaluation findings pertaining to implementation and use them to develop implementation strategies for wider roll out of LC and BCC.

Methods: BCC is used by people with breast cancer offered genetic testing as part of routine care at nine hospitals in Wessex. Evaluation methods include documentary analysis, interviews and questionnaires. LC is available in prototype version to Lynch syndrome carriers facing decisions about cancer risk management such as taking daily aspirin and risk-reducing gynaecological surgery. LC users are invited to complete an evaluation questionnaire.

Results: Most patients and healthcare professionals found LC and BCC easy to use and understand and would recommend them to others. Patients deciding whether to have genetic testing were more certain about their choice after interaction with BCC. Successful implementation of BCC by mainstream breast oncology teams in each hospital was influenced by wider contextual factors, such as existing practices, composition of care teams and local strategies for signposting patients to the PtDA.

Conclusion: By analysing barriers to, and facilitators of successful implementation of BCC and LC, we can make recommendations for strategies to implement BCC in other geographical areas, and roll-out LC into routine clinical practice.

……

A Psycho-oncology Equality, Diversity and Inclusion Community of Practice Can Make a Difference

Dr Justin Grayer[1], **Dr Sahil Suleman**[2]
[1]Royal Marsden NHS Foundation Trust, UK, [2]University Hospitals Birmingham NHS Foundation Trust, UK

Background: People with cancer who belong to minority groups and/ or who have specific characteristics, are less likely to experience equity of access, outcomes and experience.

Aims: To create a Community of Practice (CoP) for people working in Psycho-oncology services and research, across sectors (i.e. NHS, academia, private and charity) to talk about equality, diversity and inclusion (EDI) to enhance the equity of service and research access, outcomes and experience.

Methods: Quarterly one hour online meetings: guidance/ literature sharing in the 'chat', 'small and big EDI wins' to share ways of promoting EDI, a brief presentation on a topic by a CoP member followed by discussion.

Results: Eight EDI CoPs have been delivered, with up to 40 attendees on a given CoP, on the following topics: dementia, learning disabilities, LGBT+ and intimacy, deafness, ethnicity, age, deprivation, carers. Following the first four CoPs, a survey was sent to 161 attendees and completed by 35 (22%) attendees: nearly all respondents were from the Psychological Professions (94%) and from the NHS (92%); most were from London (33%) or the South West (30%) with others from across England; most had attended one (33%) or two (30%) CoPs; respondents said that the CoP was relevant to their practice (94.2% 'strongly agree' or 'agree') and impacted their work (82.3% 'strongly agree' or 'agree'), and 100% would recommend it to others.

Conclusion: A psycho-oncology EDI CoP provided members with a space in which to explore a range of relevant topics in a way that enhanced their practice and they would recommend to others; more work is required to increase the diversity of membership geographically; results are based on a limited survey response.

……

What defines mental wellbeing in bladder cancer patients: A Systematic Review

Anna Haire[1], Guilio Francolini[2], Tobias Hauser[3], Prof Richard T Bryan[4], Prof Mieke Van Hemelrijck[1]
[1]King's College London, UK, [2]Careggi University Hospital, Italy, [3]Barmherzige Brüder Hospital, Germany, [4]University of Birmingham, UK

Background & Aims: Bladder cancer (BC) patients frequently report that their diagnosis has a significant impact on their mental health and quality of life (QoL); reviews to date have focused on either identifying the incidence of specific mental health disorders (MHD) or assessing overall Health-Related QoL. The concept of mental wellbeing (MW) provides a broader understanding of mental health, as it considers more than the just presence or absence of MHD. Therefore, this systematic review aims to understand what contributes to a wider definition of MW specific to BC patients.

Methods: We followed PRISMA guidelines and the Joanna Briggs Institute (JBI) guidance for systematic reviews of observational epidemiological studies reporting prevalence and cumulative incidence data. A wide search strategy, focused on various components of MW, was conducted in PubMed, Embase, and APA PsycINFO electronic databases using Condition, Context, Population selection criteria. Risk of bias was assessed using JBI appraisal tools. Data on patient, disease, MW issue, and study characteristics was extracted.

Results: 6289 studies were identified; after screening 140 articles were included for review. BC patients experience a range of MW issues throughout their cancer journey. Included studies report 28 different issues, which can be categorised into different domains of MW: clinical MHD diagnoses, cancer-related issues (e.g.

fear of recurrence), overall emotional functioning/wellbeing, general anxiety and/or depression, and other miscellaneous components associated with poor MW (e.g. distress). Positive components of MW (e.g. hope) were also measured in some studies.

Conclusion: BC patients clearly struggle with a variety of MW issues that arise as result of their diagnosis. Future work should focus on delineating potential associations between time-points in the BC patient pathway and the development of specific MW issues. A strategy to identify BC patients at risk of poor MW and to promote positive components of MW is essential.

……

Enhancing Psychosocial Cancer Care: Insights from Patients, Clinicians, and developing and testing the implementation of a patient reported experience measure

Dr Jenny Harris[1], Zoe Clothier[1], Agnieszka Kehinde[2], Prof Jo Armes[1]
[1]University of Surrey, Guildford, UK, [2]Royal Surrey NHS Foundation Trust, Guildford, UK

Background: Cancer diagnosis and treatment pose significant psychological challenges for patients, often leading to unmet psychosocial care needs. Simultaneously, clinicians may experience stress and burnout, exacerbated by increased workloads, which impacts their ability to provide psychosocial care. Addressing both patient and clinician needs is crucial for improving care quality and outcomes.

Aims: This quality improvement study aimed to identify priorities in psychosocial cancer care from patients and clinicians' perspectives, adapt and pilot test a psychosocial Patient Reported Experience Measure (PREM), and develop recommendations for local practice.

Methods: Work Package 1 (WP1) involved semi-structured interviews with cancer patients and clinicians (N=21) analysed using Framework Analysis to identify key psychosocial care themes. Work Package 2 (WP2) included a rapid review of existing PREMs and the adaption and pilot testing of a tailored PREM. Feedback from 28 patients informed tool refinement.

Results: WP1 identified six shared themes: personalized support, accessibility, communication, care coordination, resource constraints, and psychosocial care priorities. Clinicians emphasized their own psychosocial needs and the importance of training. WP2's pilot PREM (23 items) revealed generally positive care experiences but highlighted variability in emotional support and care planning. Completion feedback indicated relevance, ease of use, and areas for refinement, such as response scale adjustments.

Conclusion: Addressing psychosocial care needs requires a dual focus on patients and clinicians. Key themes and the pilot PREM provide actionable insights for improving care delivery. Supporting clinicians' wellbeing and equipping them with psychosocial skills may mitigate burnout and enhance care quality, fostering a more resilient oncology workforce and patient community.

……

Psychosocial Interventions and Their Efficacy in Promoting Benefit Finding Among People Living With and Beyond Cancer: A Systematic Review (Protocol)

Kian Hughes[1], Prof Nicholas J. Hulbert-Williams[1], Prof Mark J. Forshaw[1], Associate Prof Lisa Beatty[2]
[1]Edge Hill University, UK, [2]Flinders University, Australia

Objectives/Background: Given the substantial psychological impact of cancer diagnosis and treatment, understanding the effectiveness of psychosocial interventions in promoting benefit finding amongst survivors is crucial. This systematic review aims to address the lack of clarity in the literature. By synthesising existing evidence, we seek to investigate the types of interventions used, their effective components, and the impact they have on enhancing benefit finding.

Methods: A comprehensive search of electronic databases (PsycINFO, OVID Medline, Web of Science, CINAHL and Scopus) was conducted to identify relevant studies. Searches resulted in 4,799 unique hits after deduplication. Of these, 110 are currently undergoing full-text screening. Data extraction and quality assessment will be performed using predefined criteria. A narrative synthesis is expected, since the data are likely to exhibit heterogeneity rendering meta-analysis unsuitable.

Results: Synthesising the results will provide an overview of psychosocial interventions and their reported effectiveness in promoting benefit finding among cancer survivors. Full-text eligibility screening is underway, with the study expected to be completed by February 2025.

Conclusions and clinical implications: Findings from this systematic review will provide valuable insights into the effectiveness of psychosocial intervention components in promoting benefit finding among cancer survivors. This systematic review will inform the development of tailored interventions to support benefit finding and guide future research.

••

Coaching-based intervention research in psycho-oncology: are we speaking the same language?

Prof Nick Hulbert-Williams[1], Dr Lee Hulbert-Williams[1], Dr Sylvie Lambert[2]
[1]Edge Hill University, UK, [2]McGill University, Canada

Background: Emotional distress is more common than psychiatric mental health diagnoses in cancer. It stands to reason, therefore, that therapeutic interventions may not be entirely appropriate for all. Barriers such as stigma and access remain problematic in accessing good quality psychosocial care. Coaching, and especially psychologically informed coaching, interventions, might be more suited to this population.

Aims: We reviewed literature on how the term coaching is being used in psychosocial oncology, paying particular attention to how those uses fit with formal definitions of mentorship, lay coaching, life coaching and specialist health/wellness and psychological coaching frameworks.

Methods: This was a narrative/conceptual review.

Results: Different types of coaching approach have variable theoretical underpinning and assumptions. They require intervention facilitators to undergo different levels of training and engage in variable types of supervision and professional development. They also look different in practice, paying more or less attention to features such as evidence-based practice and core conditions of the relationship between coach and coachee. We are witnessing an increasing number of psychosocial oncology interventions describing coaching elements to their interventions, however definitions appear ill-understood and sometimes inappropriately applied.

Conclusions: Coaching interventions need to be more clearly described and defined. We offer a proposed list of key dimension which can be used to clarify such approaches. Given the evidence for the benefits of coaching-based approaches for subjective wellbeing and personal growth, the scope for their use in psychosocial oncology is considerable.

••

Understanding the impact of cancer on everyday life: what are the online privacy experiences and needs of people with cancer?

Prof Nick Hulbert-Williams, **Lorraine Wright**[1], Prof Wendy Moncur, Dr Ryan Gibson, Dr Diane Morrow, Dr Karen Renault
[1]Edge Hill University, Ormskirk, UK

Background: Significant life transitions, such as a cancer diagnosis, require individuals to make complicated decisions about how, when, and who with, to share personal information, including in online spaces. These decisions may be driven by control need, fear of discrimination or perceived stigma. Unintended information leakage may amplify transition-related distress.

Aims: We aimed to understand the online privacy experiences and needs of cancer survivors.

Methods: As part of a larger survey, we recruited 100 cancer survivors to take part in an online, cross-sectional survey. This included closed and open question to understand better digital literacy, online privacy experiences, and needs. We then conducted experience-based co-design workshops (n=10) to enhance our understanding, and to develop potential solutions.

Results: Survey findings indicated more willingness to share information and fewer privacy concerns compared with other life transitions, though online presences were often 44nonymized. Distress related to online information sharing was low and correlated with perceived control. Workshops highlighted the value of the online space for sharing illness information with both known and unknown contacts, and as a way to 'give back' to the cancer community. The most frequently experienced online harms were misinformation, scamming and unsolicited online interactions.

Conclusion: Our work highlights the importance of the online space for cancer survivors, but also the vulnerabilities that this brings. Misinformation could lead to poor treatment related decisions; high levels of privacy concern might lead to social isolation and distress. Online behaviour is so engrained in modern life that care teams and support organisations need to be aware of the negative, as well as supportive impact, these spaces may have.

……

Setting up a Low Grade Glioma Neuropsychology Stream as part of a Psycho-Oncology service at Barts Health

Dr Maggie Karanasiou[1]
[1]Barts Health NHS Trust, UK

Background: Low grade gliomas (LGG) account for around 6.4% of adult primary CNS tumours. Recent longitudinal research has found that two thirds of LGG patients showed a cognitive decline during a 7-year follow-up, however neuropsychological assessment of cognition is not offered as standard in many Psycho-oncology services due to the lack of funding for additional Neuropsychology provision.

Aims: To set up a LGG Neuropsychology stream as part of the Psycho-oncology service at Barts Health, involving a Clinical Psychologist (CP) and Trainee Clinical Psychologists (TCPs) placed in the service offering a cognitive assessment and brief cognitive rehabilitation to patients at any stage of the LGG pathway.

Methods: A Neuropsychology stream was set up in April 2024 for LGG patients experiencing cognitive difficulties impacting on daily functioning. Seven patients (71% female) aged 30-56 (M=41.7, SD=7.4) completed the intervention, delivered by five TCPs jointly with a CP, with sessions offered ranging 3-4 (M=3.1, SD=0.3). Quantitative and qualitative feedback was collected. Additional Neuropsychology training to TCPs was provided.

Results: Three patients completed feedback forms. All patients were satisfied with practical aspects of their experience (e.g. waiting times and punctuality). On a 4-point Likert scale, all patients found the service extremely helpful in exploring their concerns, feeling listened to, and gaining an understanding of what is going on for them. All patients said it is likely or extremely likely they would recommend the service to friends and family. Patient 1 said “It helped me and my family understand what I am going through” and Patient 2 said “I feel grateful to have been offered this service. It has impacted how I approach work and daily life”.

Conclusion: It has been feasible to set up a Neuropsychology stream for LGG patients as part of an existing Psycho-oncology service at Barts Health, with promising initial patient feedback.

……

A protocol to examine the correlation between proxy and patient-reports using YOU-CAN to assess unmet needs in adolescent and young adult survivors of a central nervous system tumour

Dr Kate Law[1,2], Prof Martin McCabe[1,3], Prof Janelle Yorke[2,4]
[1]The Christie Hospital NHS Foundation Trust, UK, [2]The University of Manchester, Division of Nursing, Midwifery and Social Work, UK, [3]The University of Manchester, Division of Cancer Sciences, UK, [4]School of Nursing, The Hong Kong Polytechnic University, SAR China

Background: YOU-CAN is a self-reported measure of unmet needs designed for use with adolescent and young adult survivors of a central nervous system tumour (CNS). Some survivors of a CNS tumour experience cognitive impairment that may limit their ability to self-report. Furthermore, parent/carer/partner perspectives of unmet needs may differ from those of the patient, especially where the young person lacks awareness of their own limitations.

Aim: This mixed methods study will: compare proxy (parent/carer/partner) and patient responses of YOU-CAN, gain a greater understanding of the unmet needs perceived by parents/carers/partners and, examine how well the content of YOU-CAN reflects the perceptions of unmet needs perceived by parents/carers and partners.

Method: Patients who complete YOU-CAN as part of their routine care will be invited to ask someone who knows them well, ie. parent/carer/partner, to complete a copy of YOU-CAN and a measure of quality of life for carers (n=50). Proxy participants will be invited to take part in a semi-structured interview (n=10-20) to elicit a greater understanding of unmet needs from their perspectives.

Results: Pearson correlation, intraclass correlation coefficients (ICC) and Student t-tests for paired data will be used to compare patient and proxy reports for individual items and the overall score. The ICC and 95% confidence intervals will be classified poor (<0.50), moderate (0.50 to 0.<75), good (0.75 to 0.90) and excellent (>0.90). Qualitative data will be thematically analysed.

Conclusion: This study will provide a greater understanding of: the correlation between patient and proxy reports of unmet needs using YOU-CAN, what unmet needs are perceived by parents/carers/partners, understand how well the content of YOU-CAN reflects the perceived unmet needs reported by a proxy. This has clinical implications to improve our routine assessment of unmet needs, particularly for those who are not capable of self-report.

……

The development of a needs assessment tool (NAT) for adolescent and YOUng adult (16-39 years) survivors of a CentrAl Nervous system tumour (YOU-CAN).

Dr Kate Law[1,2], Prof Martin McCabe[1,3], Prof Janelle Yorke[2,4], Dr Sabine van der Veer[5]
[1]The Christie Hospital Nhs Foundation Trust, UK, [2]The University of Manchester, Division of Nursing, Midwifery and Social Work, UK, [3]The University of Manchester, Division of Cancer Sciences, UK, [4]School of Nursing, The Hong Kong Polytechnic University, SAR China, [5]Division of Informatics, Imaging and Data Science, The University of Manchester, UK

Background: AYA survivors of a central nervous system (CNS) tumour experience lower quality-of-life compared to survivors of other cancers, and experience ongoing side-effects which require life-long follow-up. A consistent approach to identifying unmet needs is essential for equitable, person-centred support throughout the care continuum, validated instruments available to assess unmet need for this specific population are lacking.

Aim: Develop and validate a needs assessment tool (NAT) for adolescent and YOUng adult (16-39 years) survivors of a CentrAl Nervous system tumour (YOU-CAN).

Method: Phase 1: Item generation and cognitive interviews were used to ensure items were understandable. Phase 2: Eligible participants from four NHS clinics were invited complete the draft NAT and hierarchical and Rasch analysis were used to refine the final item-set. Phase 3: Patients completed YOU-CAN in routine care. Semi-structured interviews with patients and clinicians examined the feasibility of YOU-CAN.

Results: Phase 1: 207 potential items generated from a systematic review of 29 qualitative studies were reduced to 41 in discussion with clinical experts and patient representatives. Thematic analysis of cognitive interview data (n=8) resulted in a draft NAT (49-items). Phase 2: Hierarchical analysis and Rasch analysis using data from 128 completed questionnaires identified 33 items for removal, producing YOU-CAN (16-items). Correlation with other questionnaires was acceptable, demonstrating construct validity (Pearson r=0.43 and r=0.590). Phase 3: Pilot data suggested YOU-CAN may help patients (n=6) to identify and discuss unmet needs that would not have otherwise been raised.

Conclusion: YOU-CAN is a valid and reliable measure of unmet need. AYA survivors of a CNS tumour were involved in the design, meaning YOU-CAN has good face validity. Young people contributed to item design and features of YOU-CAN overcome possible cognitive challenges that could be faced when completing lengthy questionnaires. Pilot data suggests YOU-CAN may be a useful tool in routine follow-up.

Establishing a Neuropsychological Rehabilitation Clinic for Childhood Brain Tumor Survivors

Bushra Masalha[1,2], **Ruth Carmon Filut**[1], Shlomo Tekuzener[1]
[1]Hadassah Medical Center, Hospital, Ein Kerem, Israel, [2]Hebrew University of Jerusalem, Israel

Background: Pediatric brain tumor survivors often experience neurocognitive deficits, emotional distress, and academic challenges that hinder developmental milestones. These late effects, varying in severity and progression, often go undiagnosed or untreated due to a lack of specialized neuropsychological care, particularly in oncology. Challenges are exacerbated for underserved populations, due to systemic and logistical barriers. This project seeks to address these disparities, improving outcomes and quality of life for survivors.

Aims: This initiative bridges critical gaps in pediatric neuro-oncology care, enabling early identification, diagnosis and tailored interventions, aiming to improve survivors' emotional, cognitive, and social integration.

In addition, it establishes a professional framework for addressing pediatric psycho-social oncology and neurocognitive challenges, promoting rehabilitation and delivering culturally sensitive services.

Methods: The Clinic employs a multidisciplinary approach, integrating needs, assessments and evidence-based interventions. It trains psychologists to specialize in pediatric neuropsychology, providing individualized rehabilitation programs. Services include psychological therapy, neuropsychological assessments, and tailored educational and social support. The clinic prioritizes accessibility, providing care to diverse populations, including Israeli and Palestinian children. Children and families are supported throughout active treatment, rehabilitation and reintegration of the child to its natural environment and normative development trajectories.

Results: The program engaged 50 Israeli and Palestinian families, completed 12 neuropsychological assessments, and referred 10 children to specialized educational frameworks. 45 children received advocacy for tailored school programs, while 8 cases involved welfare services. Therapeutic interventions included psychological therapy for 20 families and referrals for 10 others, addressing diverse psychological and educational needs.

Conclusion: This project emphasizes the importance of tailored, long-term care for rehabilitation of pediatric brain tumor survivors. Future plans include expanding services to children with neurocognitive and psychosocial challenges from other cancer types. In addition, developing a sustainable, cross-border collaboration model to support survivors throughout life, ensuring their reintegration into society and improved prospects for adulthood.

* * *

“That’s what’s frightening about it, because it doesn’t grow in the same way”: unmet needs of people with Lobular Breast Cancer regarding recognising and reporting recurrence

Dr Lauren Matheson[1], Hilary Brown[1], Dr Helen Coulthard[2,4], Prof Sara MacLennan[3,4], Prof Iain Williamson[2], Claire Turner[4], Jan Rose[5], Lesley Turner[5], Prof Jo Brett[1], Dr Anne Kendall[6], Sarah Cooper[6], Dr Verna Lavender[7], Prof Gozde Ozakinci[8], Amanda Shewbridge[9], Dr Nicky Levitt[10], Prof Eila Watson[1]
[1]Oxford Brookes University, UK, [2]De Montfort University, UK, [3]University of Aberdeen, UK, [4]Lobular Breast Cancer UK, UK, [5]Patient and Public Involvement (PPI) member, UK, [6]Great Western Hospitals (GWH), Swindon, UK, [7]Guy’s and St Thomas’, UK, [8]University of Stirling, UK, [9]Breast Cancer Now, UK, [10]Oxford University Hospitals Foundation Trust (OUHFT), UK

Background: Around 15% of breast cancer (BCa) patients have Lobular Breast Cancer (LBC), the second most common BCa subtype. LBC is different to ductal BCa in terms of initial and recurrence symptom presentation and growth - approximately 8% of LBC patients will develop either a local or distant recurrence. Mammography is much less effective at identifying recurrences for this group. Few studies to date have specifically explored the experiences of people affected by LBC.

Aims: We aimed to understand people’s experiences towards recognising and reporting signs of LBC recurrence during follow-up, to inform intervention development.

Methods: Qualitative interviews and workshops with LBC patients were conducted, either in ‘patient and public involvement’ (PPI) work (n=18), or part of a wider research study (n=6). People with LBC were recruited through charities and social media. Data was analysed using Thematic Analysis.

Results: During follow-up, participants expressed unmet needs regarding a lack of support or information regarding LBC recurrence (e.g. signs or symptoms) by healthcare professionals (HCPs). Participants’ diagnostic experiences such as feeling dismissed by HCPs, together with the awareness of LBC ‘differences’ contributed to a loss of confidence and trust in HCPs and scanning, and a loss of confidence and belief in the importance of self-surveillance (i.e. regular breast awareness). This negatively impacted on fears of recurrence, particularly the fear of future recurrences being missed. Support organisations were a valuable source of LBC specific support and information. A future intervention was deemed important (an interactive, digital resource, ideally with a guided discussion on recurrence), to increase LBC-specific knowledge, empowerment, and self-efficacy for self-management.

Conclusion: Findings have informed the co-design phase of an intervention aiming to increase self-efficacy for, and overcome barriers to, recognising and reporting signs of BCa recurrence, ensuring that this intervention addresses the needs of people affected by LBC.

……

Patient experiences and preference of treatment for Multiple Myeloma (iPREFER)

Melissa Perry[1], Dr Kate Law[1], Ramsay Lochhead Devaraj[1], Fay Ashby[3], Dr Sally Taylor[1,2]
[1]Christie Patient Centred Research, The Christie NHS Foundation Trust, UK, [2]Division of Nursing Midwifery and Social Work, School of Health Sciences, Faculty of Biology Medicine & Health, The University of Manchester, UK, [3]Cell Centric Ltd, Little Chesterford, UK

Background: Each year in the UK, approximately 6,000 people are diagnosed with Multiple Myeloma (MM). Main treatments for MM are targeted cancer drugs, chemotherapy, steroids, and stem cell transplants. The administration, duration, and frequency of these treatments is variable, and the usual methods of administration include oral, intravenous (IV), and sub-cutaneous. Patients often live many years with MM undergoing multiple lines of treatment. Due to the multiple treatment lines MM patients can receive; it is important to understand patients' experiences of different treatment options and their treatment preferences.

Aims: The aim of this study was to explore the experiences of people receiving treatment for MM, understand what matters most when making treatment decisions, explore how experiences differ across different treatment lines and determine if they have any treatment preferences.

Methods: A qualitative study using semi-structured interviews. Patients were eligible if they had a confirmed diagnosis of MM and had received at least five lines of treatment. Interviews were conducted using a pre-defined interview schedule focusing on their experiences of oral anticancer therapy and bi-specific antibody or IV therapy treatment. Interviews were recorded and transcribed verbatim. Interviews lasted approximately 47 minutes and were analysed using inductive thematic analysis.

Results: Thirteen patients were approached; 9 consented and were interviewed; two declined; one became ineligible, and one was lost to follow-up. Four key themes were identified: Living with multiple myeloma and quality of life; Decision making and information; treatment experience, and treatment preference.

Conclusion: Participants have shown a willingness and tolerance to accept treatments that significantly impact all aspects of their everyday life, quality of life, and relationships, to achieve their goals of care. The findings highlight the need for healthcare professionals to inform patients of the potential quality of life impacts of treatment which will support patients to make informed decisions.

……

Exploring how radiotherapy late effects services are developed in the UK, are patients routinely involved?: a mixed methods survey

Claire Powlesland[1,2], Dr Rachel Harris[3], Dr Carole Burnett[4], Prof Georgina Jones[1], Dr Siobhan McHugh[1], Dr Patricia Holch[1]
[1]Leeds Beckett University, Leeds, UK, [2]South Tees Hospital NHS Foundation Trust, UK, [3]Society and College of Radiographers, UK, [4]Leeds Teaching Hospitals, UK

Background: Annually 3,200 people are diagnosed with cervical cancer in the UK (UK) 1. Patients with locally advanced disease receive pelvic chemoradiotherapy, and brachytherapy 2. Whilst effective, 20-50% of patients report enduring gastrointestinal, urinary, sexual and neurological damage impacting quality-of-life and psychological morbidity 3, 4. While radiotherapy late-effects services exist, it is becoming increasingly important to consult patients on the development of the services they will ultimately use.

Aims: To explore how UK radiotherapy departments have involved patients in the development of services to manage the physical and psychosocial late-effects of treatment for cervix cancer.

Methods: An online survey containing 17 multiple choice and 5 open-text questions was developed in conjunction with Society and College of Radiographers (SCoR) Patient Advisory Group and distributed by the College of Radiographers to all 52 UK radiotherapy centres. Descriptive analysis of the quantitative responses was conducted using SPSS (Version 28) and for the free text responses content analysis 5-7 was utilised.

Results: We received 27 full responses (52%) from UK radiotherapy centres. Currently 15 (56%) of centres offer a late-effects service for pelvic radiotherapy and 6(22%) were in the process of setting one up. Forty-eight percent of services operated within business hours and were based in radiotherapy centres, delivered by therapeutic radiographers and treated cervix patients. Nine (33%) of services reported that patients or carers had been involved through PPIE groups to design clinic information and evaluate the service.

Conclusion: Only 15 of the UK radiotherapy centres who responded offer cervix patients access to late-effects services. Although current services have sourced feedback from patients and carers, none have co-designed their services with patients from the outset. By involving patients in co-design when reforming or developing services, it is possible to ensure that services can meet the needs of patients who will use them.

……

The development of a Patient Reported Outcome Measure (PROM) in the Adoptive Cell Therapy (ACT) setting

Grant Punnett[1,2], Dr Sally Taylor[1,2], Ashleigh Ward[1], Dr Ahmed Abdulgawad[1], Vicky Williams[1], Prof Janelle Yorke[3,2], Prof Fiona Thistlethwaite[1,2]
[1]The Christie NHS Foundation Trust, Withington, UK, [2]University of Manchester, UK, [3]The Hong Kong Polytechnic University, China

Background: Adoptive Cell Therapies (ACT) have led to improved rates of remission in haematological cancers. Like other cancer treatments, these therapies can result in adverse effects for patients which impact their quality of life. Patient Reported Outcome Measures (PROMs) can monitor symptom experience of patients and improve patient outcomes; however none have been specifically developed for ACT patients.

Aims: To develop an ACT-specific PROM to assess quality of life and symptomatology

Methods: The PROM development will involve four stages: 1) Item generation: semi-structured interviews will be used to generate draft PROM items based upon ACT patients symptom and quality of life experience 2)

Cognitive interviews: probing questioning techniques to determine patient understanding of the draft items and scales 3) Item reduction and refinement: approximately 100 patients will complete the draft PROM and other quality of life measures. Hierarchical item reduction and Rasch analysis will be conducted to reduce and refine the draft items into a final PROM 4) Pilot testing: ten patients will complete the PROM to assess data completion and determine acceptability.

Results: Twenty ACT patients were interviewed for stage 1. Thematic analysis generated items relating to symptoms, psychological experience and impact on life. Symptoms identified included fatigue and others related to Cytokine Release Syndrome (CRS) demonstrating significant impact on psychological experience and day to day life. Eight patients participated in cognitive interviewing, which resulted in removal and modification of some items. 30 items remained as part of the draft PROM. Recruitment for stage 3 is currently ongoing.

Conclusion: A PROM for ACT patients may be of benefit in clinical practice to monitor symptom experience and to assess how the treatment impacts patients quality of life.

* * *

Developing a 21st century model of nurse-led follow-up after curative germ cell tumour treatment

Gwen Saalmink[1,2], Prof Dan Stark[1,2], Dr Kate Absolom[1], Dr Sue Hartup[1,2], Prof Lynn Calman[3], Dr Lisa McCann[4]
[1]University Of Leeds, UK, [2]Leeds Teaching Hospitals NHS Trust, UK, [3]University of Southampton, UK, [4]Strathclyde University, UK

Background: Due to improved medical treatments, there is growing demand for follow-up care for people living after cancer. This needs to be integrated into a stretched NHS.

Germ cell tumour (GCT) treatment is very successful, meaning almost all patients require follow-up care. Currently, follow-up is burdensome on patients and services, not tailored to patients' needs and often inequitable. Approaches to overcome this have been successfully tested in some UK locations.

The NHS Long Term Plan emphasises utilising technology well, to deliver easily and conveniently accessible care. Remote practices within cancer follow-up are becoming more commonplace, however these are often patient-initiated or symptom-based, making them unsuitable for GCT patients.

The COVID-19 pandemic necessitated adopting remote approaches in GCT follow-up which has led to an increased desire for structured implementation. Currently, no consensus exists as to how and what works, to widen the use in GCT.

Aims: This project aims to improve patients' outcomes and reduce the strain on clinical services, by developing a nurse-led remote follow-up system in GCT and an evaluation toolkit to guide its implementation nationally.

Methods: The project consists of 4 interconnected workstreams:

1. Mixed method systematic review on remote intervention implementation during cancer follow-up using the RE-AIM framework.
2. Qualitative analysis of patients' needs of follow-up through structured interviews.
3. Consensus and training needs analysis on key components of nurse-led remote follow-up.
4. Stakeholder workshops, to design future implementation studies of remote GCT follow-up.

Results: This is an ongoing project; no results are available yet.

Conclusion: The project will positively impact patients and the NHS by producing an implementation and evaluation toolkit for novel, nurse-led GCT follow-up: creating a personalised follow-up pathway for patients, reducing waiting times and increase medical capacity for patients with the most active or complex medical post-treatment needs.

How were women affected psychologically by their experiences of being diagnosed and treated for ovarian cancer during the covid-19 20/21 restrictions? A qualitative study.

Kayleigh Sanders[1], Dr Michael Baliousis[2], Dr Mike Rennoldson[2]
[1]Lincolnshire Partnership NHS Trust, England, [2]Nottingham University Hospitals NHS Trust, England

Background: Ovarian cancer is a life-altering diagnosis. However, limited research exists on how the Covid-19 20/21 restrictions influenced the experiences of women receiving diagnoses and undergoing treatment. The pandemic created new challenges in healthcare delivery, social isolation, and emotional well-being, highlighting the need for a deeper understanding of these compounded experiences.

Aims: This study aimed to explore the psychological impact of ovarian cancer diagnosis and treatment on women during the Covid-19 20/21 restrictions. It sought to identify key emotional and psychological responses, as well as the role of support networks during this unprecedented time.

Methods: A qualitative approach using reflexive thematic analysis was employed. Twelve women diagnosed with Stage 3 or 4 ovarian cancer participated in remote, semi-structured interviews. Reflexive thematic analysis was used to identify patterns and insights within the data, allowing for a comprehensive understanding of the participants' experiences.

Results: Three main themes developed from the analysis, with several sub-themes: (1) Loss of identity – women reported significant changes to their self-perception during diagnosis and treatment. (2) Importance of a support network – social support systems, both in-person and virtual, were crucial in maintaining emotional well-being. (3) Diverse psychological and emotional responses – participants exhibited varying responses to their diagnosis, with some experiencing a need to distract themselves, while others reported the importance of living in the present moment.

Conclusion: This study highlights the complex psychological experiences of women undergoing ovarian cancer treatment during the Covid-19 20/21 restrictions. The findings emphasize the importance of robust support networks and the need to address changes in identity and emotional health throughout the cancer journey. Future research should further investigate identity changes and their psychological impact, particularly during health crises. The results also underscore the need for pandemic-specific strategies to support patients' emotional and psychological needs in oncology care.

Feasibility and acceptability of a virtual learning module for navigating angry conversations in clinical encounters

Dr Valerie Shilling[1], Rachel Starkings, Prof Dame Lesley Fallowfield
[1]University Of Sussex

Background: The current difficulties experienced by patients and their families in receiving timely appointments regarding diagnostic test results and treatment for diseases such as cancer can often result in frustration and angry exchanges in clinic. Effective communication to handle such situations is vital; virtual learning (VL) may offer a useful means to deliver training.

Aims: To examine the feasibility and acceptability of VL for communication skills training using a module developed to help navigate conversations with angry patients and relatives in a one-stop breast cancer and urology clinic. The programme can be delivered via virtual reality headset or desktop application.

Methods: Fourth and fifth year medical students were randomly allocated to receive the module via headset or desktop. Pre-intervention, participants completed the SE12 self-efficacy questionnaire, a 5-item confidence measure, and free-response study specific survey. Post-intervention, they completed a study specific survey, with fixed and free responses, the confidence measure, and the UTAUT2 questionnaire on acceptance and use of technology. Quantitative data were analysed descriptively, conceptual content analysis was applied to free responses.

Results: Twenty students took part; scores on the SE12 did not differ significantly between intervention arms. Confidence improved across all learning objectives. Responses to the UTAUT2 indicated acceptance of VL. Nineteen categories for free text responses were developed. Participants valued the opportunity to practice, and the psychological safety provided by VL. Initial apprehension that VL would not feel realistic was largely reversed post-intervention however participants noted that role play with actors had greater realism. Students expressed preference for a combination of VL, whichever modality, and face-to-face teaching and role play.

Conclusion: Participants were positive about the learning experience, found the training acceptable irrespective of mode of delivery, and felt that they had been provided with useful skills and techniques. Educational programmes should consider including VL alongside face-to-face practice.

……

BRIGHTLIGHT_2021: Is coordinated care important for improved patient-reported outcome in teenage and young adults with cancer?

Prof Rachel Taylor[1,2], Prof Cecilia Vindrola Padros[1], Dr Elysse Bautista-Gonzalez[1], Dr Lorna Fern[1], On behalf of the BRIGHTLIGHT_2021 Study Group[1]
[1]University College London Hospitals NHS Foundation Trust, London, UK, [2]University College London, London, UK

Aim: BRIGHTLIGHT_2021 aimed to assess patient-reported outcomes (PRO) and explore whether the culture of TYA care had evolved to enable inter-organisational collaboration under joint-care models.

Methods: A survey including PROs was administered to TYA newly diagnosed with cancer, recruited from across England. Mixed effects models compared between all-PTC, no-PTC or joint-care. Simultaneously, rapid ethnography was conducted across the same organisations, involving semi-structured interviews with healthcare professionals in both the PTC and DH. Data were analysed against D'Amour's structuration model through framework analysis.

Results: The was no difference in quality of life, social support, illness perception, anxiety or depression according to place of care but TYA who had no-PTC contact had great perceived health status. There was variation across the different dimensions of inter-organisational collaboration. Coordinated care was mostly developing, but there was full collaboration for a shared vision. Processes for sharing information were not streamlined, so there were cases when information could not be shared between organisations. Interventions to achieve coordinated care, such as an outreach team, supported the delivery of joint-care but these were not available in every region.

Conclusions: While there were differences in PRO reported in the 2012_BRIGHTLIGHT cohort, this was no longer the case in the 2021 cohort. This could be explained in part by more developed collaboration and coordination of care between the DH and PTC. The implementation of the service specification will require resources to extend the delivery of interventions to support coordination and collaboration, allowing the commissioned model of care to be delivered safely.

······

Longitudinal study examining the relationship between illness perception, perceived social support, and quality of life in adolescents and young adults with cancer

Dr Bethany Wickramasinghe[1], Prof Richard Feltbower[2], Dr Lorna Fern[3], **Prof Rachel Taylor**[3], On behalf of the BRIGHTLIGHT Study Group
[1]University College London, UK, [2]University of Leeds, UK, [3]University College London Hospitals NHS Foundation Trust, UK

Background: Adolescent and young adults (AYA) often face unique psychosocial challenges that can impact their quality of life (QoL) after a cancer diagnosis. Evidencing their unique psychosocial needs can support the development of targeted interventions to support them living with and beyond diagnosis.

Aims: To examine the relationship between AYA perceived social support and illness representation, exploring its evolution over the course of treatment and survivorship.

Methods: This was secondary analysis of the BRIGHTLIGHT dataset, a longitudinal cohort study of 830 AYA newly diagnosed with cancer aged 13-24 years in England. We examined perceived social support, self-reported illness perception and the psychosocial domain of quality of life (PS_QoL). Multi-level modelling examined associations across the study period. A patient advisory workshop was held to contextualise the results.

Results: Females reported overall lower PS_QoL. Greater perceived social support from friends was associated with poorer PS_QoL. Greater perceived social support from friends was also related to two key domains of illness perception (experiencing more side-effects from cancer and feeling a greater impact of cancer in general) as well as spending more time in hospital and reporting poorer communication from the cancer specialist. Young people interpreted that support from friends may sometimes lead to social pressure, with expectations to appear positive or resilient. They described often feeling overwhelmed by the emotional needs of friends offering support, or a heightened sense of isolation. These feelings may stem from an increased awareness of cancer's impact or shifts in social dynamics, where relationships become more focused on cancer support than shared experiences.

Conclusion: While previous studies of adult cancer patients demonstrate the positive psychosocial impact of support from adult communities and spouses, our findings highlight the psychosocial complexity of social support from friends in mediating illness representation and fostering positive psychosocial outcomes among TYA cancer patients.

PROMOTE - Exploratory research into the PeRceptions Of cancer and clinical trials amongst Muslim wOmen with breasT cancEr.

Lorraine Turner[1,2], Dr Sally Taylor[1,2], Prof Fiona Thistlethwaite[1,2], Prof Janelle Yorke[2]
[1]The Christie NHS Foundation Trust, Withington, England, [2]The University of Manchester, Manchester, England

Background: Despite rapid diversification across the cancer population, many racial and ethnic minority groups are underrepresented within clinical trials. Limited research has been conducted in the UK to explore the interplay between Muslim faith and cultural influences and their experience of cancer, their health beliefs and treatment decision making, in particular clinical trial participation. There is evidence of unconscious bias amongst healthcare professionals which needs to be explored to improve clinical trial participation amongst ethnic minority groups.

Aims: To explore how Muslim women's religion and cultural norms impact the perceptions and experience of breast cancer and participation in clinical trials for patients, their families and HCPs responsible for their care.

Methods: The study follows a three phased mixed-methods design. Phase 1) Semi-structured interviews to explore the perceptions and experience of cancer, cancer treatment including clinical trials amongst women and their families who are Muslim (n=12-15 & 8 immediate family). Phase 2) Online survey to explore Health Care Professionals (HCPs) experience of religious and cultural norms influencing patient's perceptions of cancer, cancer treatments including clinical trials and initiatives that support participation in cancer clinical trials for ethnic minority groups. Phase 3) Community-centred participatory workshops (n=4) based on the World Café method with patients, family members and HCP to co-design a faith-based intervention that will help increase awareness, understanding and participation of cancer clinical trials (6-10 women & 5 immediate family members, 2 HCP).

Results: Recruitment for phases 1 and 2 is underway. To date, two women have been interviewed for phase 1 and ten healthcare professionals have completed the online survey. We anticipate that phases 1 and 2 will be completed by early March 2025.

Conclusion: Study findings will be used to co-produce appropriate, culturally & spiritually sensitive recruitment methods, cancer and research literacy and inform cultural competency training for HCP.

Exploring the Role of a Second-Generation Mindfulness-Based Intervention for Improving Quality of Life, Pain Management, and Psycho-Spiritual Wellbeing in Cancer Patients: A Mixed-Methods Investigation

Chloe Wells[1]
[1]University of Derby

Background: Cancer patients often experience significant psychological distress, impacting their quality of life and wellbeing. Traditional mindfulness-based interventions (MBIs), such as MBCT and MBSR, have been effective in addressing anxiety and depression. However, first-generation MBIs may not fully encompass the complexities of the cancer experience, particularly in integrating spiritual and existential dimensions. This study evaluates the effectiveness of Meditation Awareness Training (MAT), a second-generation MBI that integrates Buddhist concepts such as impermanence and emptiness. MAT offers a more holistic approach, addressing both psychological and psycho-spiritual dimensions of wellbeing.

Aims: To assess the impact of MAT on quality of life, psychological wellbeing, pain management, and psycho-spiritual wellbeing among cancer patients, and to explore participants' experiences with the intervention.

Methods: Phase 1 is an RCT with the MAT intervention group and a treatment-as-usual control group. Participants will complete psychometric tests at baseline, mid-intervention, post-intervention, and at a six-month follow-up. Phase 2 includes qualitative semi-structured interviews with a subset of MAT participants at one-month and six-month follow-ups to gain insights into their experiences. Phase 3 captures weekly anonymous online diary entries from MAT participants during the intervention to document their reflections.

Results: It is anticipated that participants in the MAT group will demonstrate reductions in psychological distress and improvements in pain management and quality of life compared to the TAU group. Qualitative data will provide deeper insights into the participants' experiences and the influence of Buddhist wisdom teachings on their perspectives regarding illness and life. Results from the systematic literature review suggests these concepts are beneficial.

Conclusion: This research aims to bridge the gap between first-generation and second-generation MBIs by incorporating Buddhist principles that address the spiritual and existential concerns of cancer patients. The findings could inform clinical practices in oncology, offering a more comprehensive approach to enhancing the wellbeing of cancer patients.

……


BPOS