CANcer BEhavioural Nutrition and Exercise FeasibilIty Trial (CanBenefit); Phase I qualitative interview findings.

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Abstract

Background: Older people with lung cancer are often frail and unfit due to their cancer and co-morbidities and may tolerate cancer treatments poorly. Physical activity (PA) and a healthy diet offer quality of life benefit to people with cancer before, during, and post treatment. However older adults are poorly represented in the clinical trials on which recommendations were made.

Objective: To assess the acceptability, usefulness, and practicality of delivering a tailored wellbeing (PA and nutrition) intervention for older adults with lung cancer before, during and after cancer treatments (chemotherapy and/or immunotherapy).

Methods: Semi-structured interviews conducted with ten lung cancer and two mesothelioma patients, ≥70 years and ten informal carers, and nine Multidisciplinary Team (MDT) members. A topic guide covered the acceptability, usefulness, and practicality of a wellbeing intervention as well as specific feedback on individual components. Data were subjected to thematic analysis.

Findings: Four themes were generated: current lack of wellbeing care in clinical work; preferred “can have” dietary and “can do” PA advice; peer support as facilitating factor; and barriers to compliance including patients’ psychological and physical issues as well as current cancer pathway and staffing issues.

Conclusion: Older adults with lung cancer would welcome a proactive, clear and instructive, wellbeing intervention. Many barriers to compliance exist, particularly before and during cancer treatments due to the psycho-social impact of diagnosis, and the effects of cancer treatment. The intervention must be tailored to individual need and address physical limitations, psychological and social welfare in addition to PA and nutritional advice.

Introduction

Older adults with cancer have poorer outcomes and survival rates than younger people.(1, 2) This is partly due to inappropriate withholding of cancer treatments (3), and partly because some will tolerate cancer treatments such as immunotherapy or chemotherapy less well, if at all, due to comorbidities and frailty which render them vulnerable.(4) Frailty is a clinical syndrome characterised by lower functional reserve, increased vulnerability to dependency, and mortality after minor stressor events.(5) It is associated with increased risk of falls, disability, hospitalisation and death.(6) Frailty affects approximately 10 to 20% of people aged over 65 years and this incidence doubles in people aged 85 or older.(7, 8) Along with higher rates of sarcopenia, cachexia and nutritional deficiencies cancer treatment options may be limited and completion rates reduced.(4)

Physical activity (PA) offers significant benefits to the functional status of people with cancer (9-12) and rehabilitation among people with chronic obstructive pulmonary disease (COPD) is also known to reduce frailty short term.(13) Emerging work regarding the relationship between PA and immune function in the older person is interesting, particularly with regard to health-related quality of life (HRQoL), tolerance of cancer treatments, and health service utilisation.(14-19) This may be relevant particularly to lung cancer patients with increasing use of immunotherapy to restore anti-tumour immunocompetence.

In patients receiving chemotherapy, better nutritional status is associated with improved overall survival (20-22) and, in patients with lung cancer undergoing chemotherapy, better quality of life.(23) Nutritional interventions, including dietary counselling and attention to PA as well as nutrition advice, appear to improve patient wellbeing and treatment completions (24), but more data are needed.(24, 25)

Previous work has focused on prehabilitation (e.g. prior to surgery, therefore in those fit enough to be considered for surgery) (26, 27), maintenance during treatment (e.g. alongside chemotherapy) (10), or rehabilitation for cancer survivors following completion of cancer treatments (28, 29) with few studies including a nutritional component.(30)

However, delivering targeted programmes according to rigid points on the cancer continuum, seems artificial and inflexible. A PA and nutrition intervention started as part of best supportive care from diagnosis may improve a patient's performance status sufficiently to be considered for cancer treatment. An intervention given as part of cancer care should not stop if the cancer treatment is no longer tolerated, and questions about the ideal duration of prehabilitation in order to gain benefit and implementation in cancer pathways are unanswered. The development of such a tailored wellbeing intervention, whatever the treatment plan, may help to increase the proportion of older people able to receive and tolerate a full course of cancer treatment, and improve HRQoL and function in those receiving best supportive care only.

Current policy guidelines encourage implementation of PA interventions for all with cancer. Combined moderate-intensity aerobic and resistance exercise performed for 30 minutes, two to three times weekly for at least 12 weeks results in improvements in HRQoL both during and after treatment.(31) These recommendations are informed by trials which include few older adults with cancer and study end points may be less relevant to the older cancer population.(32) The Wisconsin Cancer and Aging Research Group (33) recognise this paucity of data recommending further work to ensure appropriate patient populations, tailored intervention, and relevant outcome measurement. This would allow robust development and testing of such interventions prior to routine implementation for all patients with cancer irrespective of age and performance status.

This study is part of a project work stream that aims to develop, and test the feasibility of an effectiveness trial of, a tailored wellbeing (PA and diet) intervention for older adults with lung cancer to deliver before, during and after cancer treatments (chemotherapy and/or immunotherapy). This paper reports on the following objectives from the developmental work;

1. To assess the acceptability, usefulness and practicality of delivering a tailored wellbeing (PA and diet) intervention for older adults with lung cancer before, during and after cancer treatments (chemotherapy and/or immunotherapy).

2. To understand what are the past and current PA and diet behaviours, and the barriers and enablers to a tailored wellbeing (PA and diet intervention) for older adults with lung cancer before, during and after cancer treatments (chemotherapy and/or immunotherapy).

A description and rationale for the final included intervention components are presented elsewhere.

Methods

Our study development and modelling design was informed by the Medical Research Council (MRC) Framework for the development, evaluation and implementation of complex interventions.(34)

Purposive sampling was used to obtain a wide range of views across two groups; i) patients with lung cancer and their informal carers and/or family members and ii) healthcare professionals.

Eligibility criteria for patients were;

- Age ≥ 70 years, active lung cancer (any histology and any stage)
- Decision for cancer treatment (immunotherapy and/or chemotherapy) or best supportive care made by the Multidisciplinary Team (MDT)
- Able to be interviewed, including sufficient use of English (or availability of suitable translator) and give informed written consent.

Informal carers and/or family members were included if they were nominated by the patient and they were able to be interviewed and give informed written consent.

Eligibility criteria for the healthcare professionals were;

- MDT members caring for patients with lung cancer attending the cancer centre (across inpatients and outpatients)
- Willing to be interviewed and give informed written consent

Patients were identified and invited to participate by a member of their clinical team at lung cancer and chemotherapy outpatient clinics held at a single cancer centre between April 2019 and November 2019. Patients were invited to participate irrespective of whether they had an informal carer and/or family members and whether or not their carer/family members agreed to take part in an interview too. Healthcare professionals were invited to participate through presentation and delivery of invitation and participant information sheets at MDT meetings, and by snowballing “word of mouth” from the lung cancer staff.

Written informed consent were obtained from all participants prior to interview. All participants were assured of confidentiality, anonymity and the right to withdraw at any stage without offering a reason. Semi-structured, in-depth interviews were conducted by FS a female, post-doctoral researcher with previous qualitative interview experience. The patient and carer/family interviews were conducted at the participants' home and the MDT interviews at the cancer centre or at the University. Interview duration was < one hour for patients and carer/family members and < 30 minutes for MDT clinicians.

A topic guide structured according to the "APEASE" criteria (35) and the key behavioural determinants (barriers and facilitators) (36) to adoption of a wellbeing (diet and PA intervention) were used for all interviews. This included the acceptability, usefulness, and practicality of a tailored wellbeing programme and specific feedback on individual components whilst allowing for unanticipated issues to be presented. All patient and carer participants were asked about their past and present PA and diet behaviour to identify key barriers and facilitators (36) to changing health behaviours (37), and the adoption of the wellbeing intervention. See Supplementary file one, Interview topic guide.
All interviews were audio-recorded and transcribed verbatim. Field notes were written on non-verbal aspects of communication. Ethical approval was granted by West Midlands-Egbaston Research Ethics Committee (19/WM/0029). The Consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist was followed. (38)

Interpretation of the results was made from a modified Grounded theory perspective (39) as the data were approached with specific research questions. The aim was to develop categories and themes to illuminate the data collected, and generate insight into the participant's, carer's and health professionals views of how a tailored wellbeing (PA and nutrition) intervention for older adults with lung cancer before, during, and after cancer treatments (chemotherapy and/or immunotherapy) should be developed. The method involved a systematic coding of the interviews, in which categories were developed and saturated with appropriate examples to demonstrate relevance to the research questions. (39)

Analysis

The anonymised transcripts and field notes were imported into NVivo Version 12 software (QSR International).(40) Thematic analysis was used in a deductive-inductive manner following a process of immersion in data, line-by-line coding, grouping of codes into initial themes, and then generation of major themes.(41) Three interview transcripts from each participant group (patients/carers v health professionals) were independently coded by two researchers, FS and HC. FS and HC then developed the agreed working coding frameworks; one for the patients and carers/family members, and one for the healthcare professionals to capture both the commonalities and differences between patient and healthcare professional data. These were used by FS to systematically code and organise the dataset which facilitated further analysis to categorise the recurrent or common themes. FS developed the themes, which were supported by HC through peer checking and by the wider research team through discussions in the research meetings. See Supplementary file two Example of thematic analysis process.

Results Demographics

Semi-structured, in-depth interviews were conducted between April and November 2019. 12 patient and carer/family interviews were conducted at the participants' home; four were individual, seven carer dyads and one interview included three family members. Nine individual MDT interviews were conducted; four at the Cancer centre, and five at the University. Data saturation was achieved.

Participants included ten patients with lung cancer, two patients with mesothelioma, ten informal carers/ family members, and nine MDT members. Patients were ≥70 years (range 70 to 81), eight male. Histological types included mesothelioma, non-small cell, adenocarcinoma and large cell neuroendocrine. The most common histology was adenocarcinoma; five patients. Cancer treatments were immunotherapy for two patients and chemotherapy for ten patients. Out of the twelve patients, three were pre, two during, and seven post cancer treatments including two who had stopped treatment due to severe side-effects. Two were starting second-line chemotherapy. Only three patients declined to participate; all were having chemotherapy treatment and felt that participation was too burdensome. None were known to the interviewer prior to interview and none of the interviewees required a translator. MDT members included; dietician, physiotherapist, lung cancer nurse specialist, medical registrar, chemotherapy nurse and therapy services manager. None of the invited MDT members declined study participation. See Table 1 Demographics of participants.

Insert Table 1 Demographics of participants

Findings

The four key themes generated by the data were; i) current healthcare provision, ii) preferred information provision, iii) peer support, and iv) barriers to the wellbeing intervention; this theme was divided into three main sub-themes; a) psychological, b) physical and c) healthcare services barriers. See Table 2 Main themes and participant quotes.

Insert Table 2 Main themes and participant quotes

Theme One: Current healthcare provision

Few participants received any formal guidance or advice on nutrition and PA before, during and after cancer treatments, and there was a particularly noticeable lack of PA instructions. Most felt that clinicians needed to be more proactive in offering advice and information, rather than waiting for the patient or carer to ask and would welcome this. Staff concurred the “invisibility” of problems unless they were specifically raised by the patient and identified that as there was no formal service or intervention to provide physiotherapy or dietary input it did not routinely happen.

Theme two: Preferred information provision

Nutritional guidance was viewed (by a few who received informal guidance) as a “can’t have” dietary list with little, if any, help given for the “can haves”, such as recipes, menus or ideas of how to cook with the recommended foods. Patients and carers preferred PA and nutritional information on a “told what to do” basis and in particular they felt that the safety of PA should be addressed. Practical advice proactively given would be helpful for patients. Staff agreed that a “can have” or “can do” list was an important facilitator to the wellbeing intervention.

Theme three: Peer support

The patients and carers expressed strong views on the need for a support group, although at diagnosis some preferred little or no social input. Most identified that the opportunity to talk to someone in a similar position, or of the same diagnosis was important, and even those who did not favour group activity felt it would be useful to meet up with other patients with lung cancer to chat about their experience, or seek reassurance about cancer treatment related side-effects. Staff also thought support groups were very important and suggested that the social interaction from a group based programme could be a potential facilitator to patient engagement in a wellbeing intervention. .

Theme four: Barriers to the wellbeing intervention

a) Psychological: diagnosis, cancer treatment and management

The psychological impact of lung cancer diagnosis was very high. In particular, patients feared imminent cancer treatment side-effects and worried over their scan results as well as the implications of this for their life expectancy and the future. This was considered a significant barrier to prehabilitation. Both patients and carers voiced views that they felt it very likely that they would struggle to engage with a wellbeing intervention. Even after successful completion of cancer treatments patients were unsure of PA and feared what next, or if a second line of cancer treatment would still work. Staff also highlighted the psychological barrier of diagnosis and the difficulty this would present to the uptake of a wellbeing intervention before the start of cancer treatments.

b) Physical: cancer treatment related side-effects and co-morbidities

Most participants reported side-effects during cancer treatments to such a degree that they thought complying with any wellbeing intervention would be difficult, if not impossible at certain times. In terms of PA the first week post chemotherapy treatment was considered the most restrictive period. Infection risk also meant that patients preferred to avoid any outside activity. Staff likewise identified that potential side-effects from cancer treatments would greatly limit the patient's ability to perform any PA and recommended an intervention design that avoided week one post chemotherapy treatment. Barriers to the nutritional intervention mostly revolved around the patient's experience of pain, nausea, metallic taste, altered smells and loss of appetite during cancer treatments. In addition, participants highlighted the fatigue and lack of energy to cook food, as well as the physical problems of trying to cook when restricted from lifting pots and pans post-surgery.

Comorbidities also featured as a barrier to involvement in a wellbeing intervention with most of the restrictions relating to PA rather than diet.

c) Health services: current clinical pathways and staff resources

The identification of patients with lung cancer who could present through multiple pathways and the short timespan from diagnosis to starting cancer treatments were highlighted as potential barriers to implementation of a wellbeing intervention, as were the problem of resources with staff already stretched to capacity.

Discussion

We found four major themes with regard to patients', carers and health professionals views on a wellbeing intervention; i) current healthcare provision regarding PA and nutrition, ii) preferred information provision iii) peer support, and iv) barriers; psychological, physical and healthcare services. All have important implications for the acceptability, usefulness, and practicality of delivering a wellbeing intervention for older adults with lung cancer before, during and after cancer treatments.

Participants identified a lack of proactive information provision at diagnosis that was complicated by the psychological impact of the cancer diagnosis. This was recognised as a barrier to information uptake and highlighted the patients' difficulty with engagement in a PA and nutritional programme prior to cancer treatment. Staff did not see the time immediately after diagnosis as a teachable moment, that is, an opportunity after a health event when a patient is receptive to receiving guidance to help change their health behaviours. (42) This is in contrast to previous studies that suggest cancer survivors are likely to consider and adopt lifestyle changes, particularly during teachable moments after diagnosis. (43, 44) It is possible that the high clinical workload found in our study adversely affected the interaction between the clinician and patient central to the creation of teachable moments. (42)

Macmillan prehabilitation guidelines seek to implement prehabilitation within existing clinical pathways for all people with cancer. (45) However, both patients and staff in this study demonstrate that barriers are high prior to cancer treatments and challenge the implementation of prehabilitation, raising concerns about restrictions under current cancer pathways and staff resource, and patient readiness and willingness to engage at this time. The staff data suggest there is little capacity and very small window of time to deliver prehabilitation such as PA within existing clinical services in keeping with previous study (46); whilst for the patient the shock of the cancer diagnosis and the fear of the proposed treatment may stop them from engaging with prehabilitation. Furthermore, anything which delays cancer treatment is unlikely to be acceptable with the worry of the cancer growing during the wait. Given the evidence base for prehabilitation is largely in better performance status patients awaiting surgery or bone marrow transplantation, blanket implementation of recommendations extrapolated to a very different patient population is unlikely to be successful or wise use of scarce healthcare resource.

Participants in our study reported that cancer treatment-related side-effects were a significant barrier to the acceptability and practicality of a wellbeing intervention rendering this challenging during treatment. This is consistent with recent qualitative study that suggest despite positive views of PA among older patients with cancer, most struggle to stay physically active during cancer treatment.(47) Following primary cancer treatment, anxiety due to uncertainties over future prognosis and future cancer treatment options, as well as pre-existing co-morbidities were identified as potential barriers that could compromise compliance.

However, despite these barriers our study participants would welcome a wellbeing programme, with data suggesting what and when PA and nutritional help would be useful. This included availability of peer support, group PA prior to and after cancer treatments, individual PA guidance during cancer treatments as well as the provision of safety information. Nutritional support was required during cancer treatments for the related side-effects, along with practical accessible advice for diet with examples of recipes, menus or ideas of how to cook with recommended food lists.

Our findings challenge the acceptability and feasibility of implementing current policy informed by clinical trials performed largely in exercise with younger patients with cancer or older patients without cancer. (25, 33) They highlight the necessity for particular attention to the uncertainties and ongoing changes in the physical, psychological and social needs of an older adult before, during and after cancer treatments. As such, tailored co-designed interventions would seem more appropriate. These data support the importance of a flexible holistic wellbeing programme, tailored to individual needs and responsive to the physical, psycho-social consequences of diagnosis, disease and treatment instead of PA and nutritional advice alone. (48) Psychological, educational and social components such as group activity, mindfulness and carer support were deemed to be key components, which may also serve to facilitate the uptake of ongoing PA and good nutrition throughout the cancer course. This is consistent with evidence that a multimodal approach incorporating physical and psychological interventions are more effective than a unimodal approach that addresses just one or the other even prior to treatment. (49)

Also, mindfulness based interventions (MBIs) such as Tai Chi, Yoga, or Qigong may be particularly useful considering the significant psychological burden in living with cancer; recent systematic review and meta-analysis of 29 RCTs that tested MBIs for 3274 patients with cancer found significant reductions in psychological distress (HADS total score). (50) Evidence that suggest MBIs benefit the psychological welfare of patients with cancer (50) and may be used to target difficult symptoms experienced by patients with lung cancer such as breathlessness, worry and insomnia. (51)

Strengths and limitations

The qualitative study recruited patients with different cancer diagnoses including adenocarcinoma, small cell and mesothelioma at varying stages of cancer treatment (pre, during and post) to generate maximum variation of data. These data have provided valuable insight into the complicated changing needs of older adults with lung cancer and help inform the design of a tailored wellbeing intervention for testing in a future feasibility trial. The inclusion of interviews with healthcare professionals highlight the potential barriers that could negate implementation of a wellbeing intervention within existing healthcare services.

The study used a pragmatic approach to allow patients' and carers' their choice of whether they wished to be interviewed alone or together. The majority of the interviews conducted were carer dyad. This allowed insight into the dynamics between the patient and the carer, and enriched the data collection on dietary concerns which often involved the carer. However, it is recognised that the presence of the carer may have limited what the patient said during interview.

A further limitation may be that only patients who were interested in PA and nutrition were recruited to the study. In addition, as these findings relate to a small sample size it is not possible to generalise to the older adult lung cancer population. Interviews are a subjective method based on the social interaction between the interviewer and interviewee, therefore social acceptability bias is possible. This could have influenced what participants reported in terms of the acceptability, practicality and usefulness of engaging in a wellbeing intervention before, during, and after cancer treatments. However to help minimise this potential bias I was careful during the interviews to ensure that none of the participants were aware of my clinical background as a physiotherapist. It is possible that my personal opinions as a researcher and a physiotherapist who is committed to the importance of PA could have introduced bias to the interpretation of the patients', carers and healthcare professionals' views of PA. Finally it has not been possible to present all of the minor findings from the analysis in this paper. A detailed description of all the individual intervention components will be reported in the future feasibility RCT.

Implications for clinical practice and research

Policy recommendations regarding prehabilitation and rehabilitation may not be applicable or acceptable in older adults with lung cancer not fit enough for radical treatment. A holistic approach tailored to changing needs from post-diagnosis/pre-treatment, during treatment to post-treatment is important. Implementation of such an intervention has important implications for staff resource and service configuration. Data from older adults with lung cancer and other cancers are needed to show whether such multi-modal interventions are possible, effective and implementable.

Conclusion

Older adults with lung cancer would welcome proactive, clear and instructive information provision for a wellbeing intervention. However, barriers to PA and dietary compliance are high particularly before and during cancer treatments due to the psycho-social impact of diagnosis, and the effects of cancer treatment. A wellbeing intervention must be tailored to individual need and include attention to physical limitations, psychological and social welfare in addition to PA and dietary advice.

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Authors' contributions: FS, CF, ML, and MJ created the concept and design of the study. FS and CF conducted the interviews, FS, HC and MJ analysed and interpreted the data, FS and MJ prepared the manuscript. All authors read and approved the final manuscript.

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