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Home-based rehabilitation in inoperable non-small cell lung cancer—the patient experience

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Home-based rehabilitation in inoperable non-small cell lung cancer—the patient experience

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Abstract

I have changed the spelling of 'program' throughout but if it has been spelt 'programme' to be in line with journal policy then please ignore these changes

Purpose

Exercise is important in lung cancer, yet most people do not meet the physical activity guidelines. The aim of this study was to characterise the views and experiences of participants with inoperable lung cancer who completed a home-based rehabilitation program~~me~~.

Methods

Ninety-two participants were recruited (45 intervention group [IG], 47 usual care). Individual semi-structured interviews were conducted with participants randomised to the IG of a trial of home-based exercise, behaviour change and symptom management. Data were independently coded by two researchers, cross-checked and analysed using content analysis with a summary of arising themes.

Results

Of the IG (25/45), 55% were interviewed: mean (SD) age 67 (13) years; male 52%; disease stage *n* (%) III = 9 (36), IV = 11 (44); radical treatment intent *n* (%) 13 (52). The majority of participants reported program~~me~~ benefits, both in the physical domain (reduced sedentary time and improved strength, fitness and function) and the mental domain (motivation to keep healthy, preventing boredom). Support to self-manage symptoms was well received and many participants reported increased confidence in managing their symptoms. Exercise enablers included having expert health professional support; motivation to be stronger and better prepared for future challenges; and having an achievable and familiar programme that was monitored.

Treatment side-effects, pain from comorbidities and the weather were exercise barriers. For the majority of participants the use of a Fitbit™ activity tracker, text message exercise reminders and an exercise diary helped to promote adherence.

Conclusions

This home-based rehabilitation program~~me~~ was acceptable to most participants with multiple benefits reported including improved fitness, motivation and ability to manage symptoms.

Keywords

Lung cancer
Physical activity
Exercise
Symptoms

Electronic supplementary material

The online version of this article (https://doi.org/10.1007/s00520-019-04783-4) contains supplementary material, which is available to authorized users.

Introduction

Physical activity (PA) guidelines for people with cancer recommend 150 minutes of moderate-intensity aerobic exercise and two to three resistance training sessions per week [1, 2]. This is based on a substantial body of evidence regarding the benefits of exercise for cancer survivors [3, 4, 5, 6, 7, 8]. In lung cancer, exercise interventions are associated with improvements in patient outcomes including exercise capacity, muscle strength and symptoms, particularly cancer-related fatigue (CRF) [9, 10, 11]. Despite these findings, PA levels remain low in people with lung cancer [12, 13, 14, 15].

Physical activity barriers and enablers in lung cancer may differ to those in other forms of cancer given higher reported symptom burden including dyspnoea, pain and anorexia [16], the presence of comorbidities and the stigma and social isolation often associated with the disease [17]. Reasons for low levels of PA are likely multi-factorial and can relate to (1) poor prognosis and rapid disease progression; (2) treatment demands and side-effects; (3) symptoms and associated comorbidities; and (4) behavioural factors including previous sedentary lifestyles, fear of symptom exacerbation and perceived lack of relevance. In addition, few patients receive specific exercise advice [18].

In advanced cancer, exercise training has demonstrated safety and benefits [19, 20, 21]; however, study attrition is often high, and session attendance and exercise adherence are frequently not reported or vary widely [20, 22]. Patients with metastatic lung cancer or in palliative care settings report high motivation [23] and self-efficacy [24] to exercise at home, primarily to maintain function and health-related quality of life (HRQoL) and enable participation in daily activities [24]. Newly diagnosed patients with lung cancer report interest in home-based, moderate-intensity exercise during chemotherapy [25]. In contrast, Cheville and colleagues attribute a lack of knowledge regarding potential benefits and lack of perceived need, to reported low willingness to participate in rehabilitation services [26]. These discordant findings raise questions regarding the acceptability of exercise programmes for people with inoperable lung cancer. We conducted a multi-disciplinary randomised controlled trial (RCT) of home-based rehabilitation for people with inoperable non-small cell lung cancer (NSCLC), at treatment commencement [27]. This qualitative sub-study sought to characterise the views and experiences of participants randomised to the intervention group (IG) to understand factors impacting on programme acceptability and feasibility. Consolidated criteria for reporting qualitative research (COREQ) guided the reporting of this work [28].

Methodology

Research team and reflexivity

Three physiotherapist researchers conducted the interviews. All had experience in managing patients with cancer and were independent of the study intervention. One had experience in qualitative research; the other two received training regarding the interview schedule and conduct from one of the study authors (LE). A minority of participants had prior contact with one of the researchers during the study recruitment process.

Study design

Participant selection, setting and sample size

Participants were recruited to the RCT from three tertiary hospitals in

Melbourne, Australia. All participants received standard medical care ('usual care'). Referral to health professionals for exercise advice or symptom management support was not part of usual care at any of the involved sites during the recruitment period. Eligibility criteria are provided in Table 1. Ethical approval was obtained as part of the RCT (HREC/14/PMCC/27) and each participant provided written informed consent prior to study involvement. The study was prospectively registered on the Australian New Zealand Clinical Trials Registry (https://www.anzctr.org.au): ACTRN12614001268639.

Table 1

Study inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Diagnosis of inoperable NSCLC	Concurrent, actively treated other malignancy (or 1-year history of other malignancy) other than non-melanoma skin cancer or in situ melanoma
Scheduled to receive treatment for the primary lung tumour other than surgery (including chemotherapy, radiotherapy or targeted therapy)	Comorbidities or evidence of pelvic or lower limb bony metastases prohibiting participation in a land-based exercise program~~me~~*
Commenced treatment ≤ 4 weeks prior to recruitment	Met PA guidelines in the past month based on self-report (150 min or more of moderate-intensity PA per week)
Aged ≥ 18 years	Current unstable psychiatric or cognitive disorder
Able to read and write English	
ECOG-PS of ≤ 2 [29]	
Clinical Frailty Scale score of < 7 [30]	
Physician-rated life expectancy of > 6 months	
Treating oncologist's approval for study involvement	

NSCLC non-small cell lung cancer, *ECOG-PS* Eastern Co-operative Oncology Group performance status, *PA* physical activity

*Participants with stable spinal, pelvic or lower limb bone metastases were eligible for inclusion following approval from the treating oncologist

Between December 2015 and February 2017, participants randomised to the IG were contacted by the researchers and asked to participate in a semi-structured interview. All interviews were conducted by telephone at a time convenient for the participant. This method was chosen as it was felt by the researchers to be less burdensome on the participant than attending the hospital for a face-to-face interview. The RCT recruited 92 (45 IG, 47 usual care) participants. To allow for intervention maturation, after enrolment of the first 20 participants, all subsequent IG participants were asked to participate in the interview prior to programme completion. This non-random sampling method is consistent with the study aim to explore participant's views and experiences of involvement in the intervention and ensured a sample size of at least 20 participants to provide confidence of major theme consistency [31].

RCT intervention

The RCT intervention incorporated 8 weeks of home-based physiotherapy aerobic and resistance training, exercise behaviour change strategies and nursing symptom self-management support. This was followed by a 'maintenance phase' consisting of a step-down in frequency of telephone contact delivered by the physiotherapist, until trial completion at 6 months. Further details regarding the intervention are available in Table 2, the online supplementary material and the trial protocol [27].

Table 2

Study intervention details

Weeks 1–8
• Initial exercise prescription completed in participant's home by the trial physiotherapist:
○ Moderate-intensity aerobic exercise (walking, cycling or swimming) commenced a minimum of 10 min twice weekly.
○ Resistance exercises (two to three times per week) commenced at 80% of a 10 repetition maximum in 2 to 3 sets including the following: sit-to-stand, squats, step-ups, heel raises, wall press and unilateral shoulder elevation and horizontal extension with free weights.
• Initial symptom assessment and self-management session conducted by telephone with the trial nurse using the ESAS to identify symptoms of most concern to participants [32]. Participants are provided with verbal and written information regarding self-management of symptoms. Please leave a space after this line as the next line should be formatted as the first line of the table 'Weeks 1-8'
~~•~~ Weekly physiotherapy and nursing telephone follow-up weeks 2–8:
○ Review adherence to prescribed exercise program~~me~~ and set exercise goals for the following week, aiming to progress towards meeting physical activity guidelines (150 min of moderate-intensity aerobic exercise and two to three resistance training exercise sessions per week).
○ ESAS used to monitor current symptoms and guide weekly symptom self-management sessions.
• Up to two additional physiotherapy home visits could be provided for participants not meeting exercise goals or when requested by the participant,
• Additional strategies to support exercise adherence included:
○ encouragement of social support from family and/or friends

○ weekday SMS exercise reminders,
○ Fitbit Zip® activity trackers,
○ exercise diaries to record daily exercise details,
○ DVD of resistance exercises.

ESAS Edmonton Symptom Assessment Scale

Data collection

The semi-structured interview schedule was devised to gather participant feedback regarding each component of the intervention, including sessions delivered by the study physiotherapists and nurses; home visits and telephone calls; participant confidence in safe performance of the exercise program~~me~~; symptom self-management; and use of study resources including exercise adherence strategies. All interviews were recorded and transcribed verbatim [33]. Participants were contacted by a researcher to arrange an interview time and informed the interviews were recorded with transcriptions de-identified using pseudonyms and stored electronically for analyses.

Data analysis

All transcripts were cross-checked for accuracy by a second researcher and coded independently by two researchers (LE and SK). The initial 11 out of the 25 interview transcripts were reviewed by the senior author (SA) to ensure interview schedule fidelity. Participant review of transcripts was not possible due to the poor prognosis of the cohort. The primary method of analysis was conventional content analysis for each interview question and a summary of the arising themes [34]. Coding of interview transcripts was completed by line-by-line assessment to derive themes using a previously developed questionnaire template (online supplementary Table E1). The researchers cross-checked codes, and disagreements were discussed until reaching consensus. Saturation was confirmed when no new themes emerged from coding the final interview transcripts [35].

Results

Sample characteristics

Seventy-one percent (32/45) of IG participants were contacted and 55% (25/45) completed telephone interviews (Fig. 1). Included participants were a mean age of 66.5 years and 11 (44%) had stage IV disease (Table 3). There were no significant demographic or clinical differences between interviewed participants and the RCT sample. Exercise programme adherence (performance of aerobic exercise at least twice weekly for six of the eight-week initial program~~me~~) was similar for those interviewed (68%), compared with the total IG (65%). Interviews were performed a median (IQR) of 35 (24–65) days post-completion of the initial 8 weeks of the program~~me~~ and the mean (SD) interview duration was 22.7 (13.7) min.

Fig. 1

Participant flow

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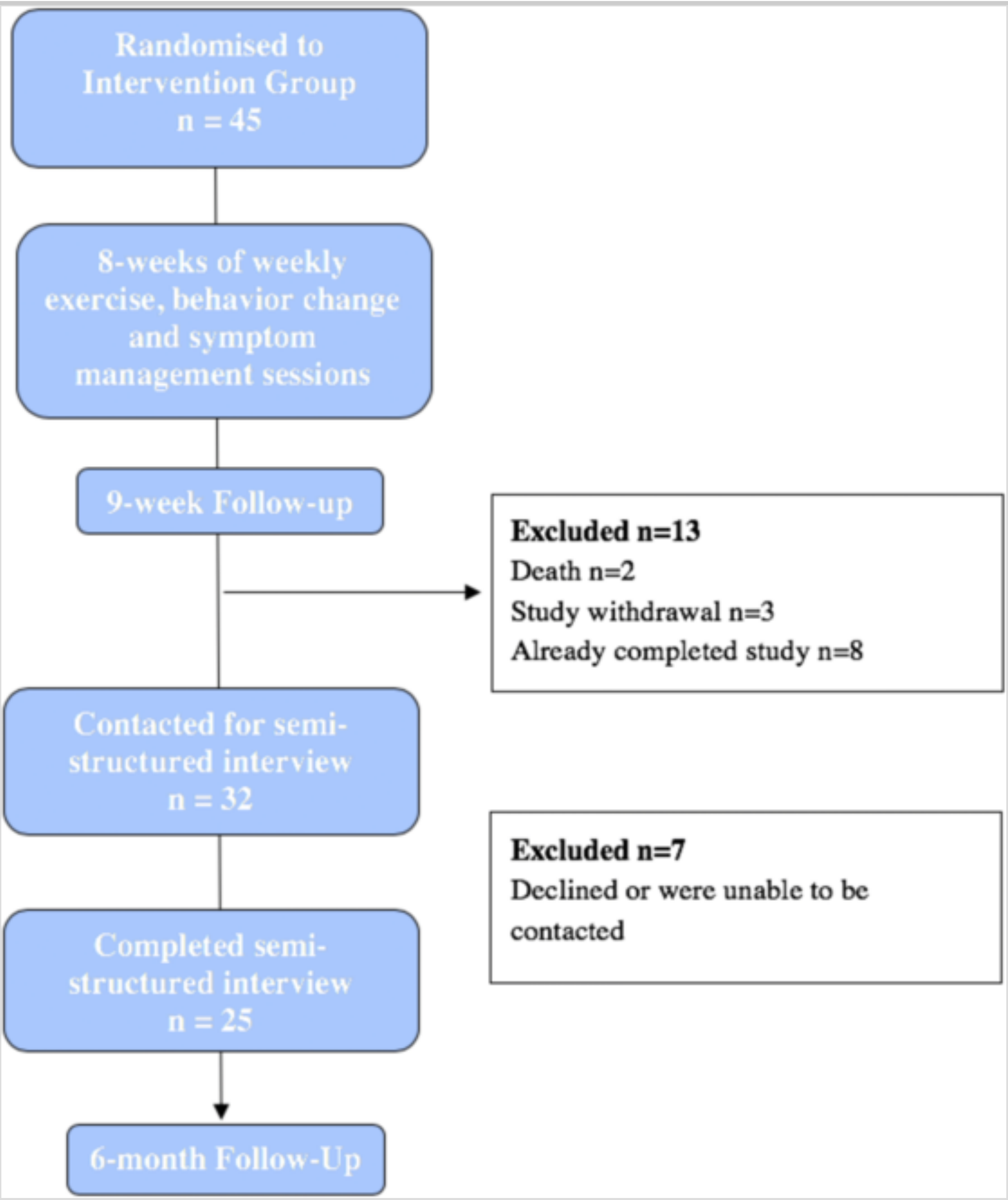

Table 3

Baseline characteristics of participants

	Qualitative nested study participants (*n* = 25)	RCT participants with follow-up who did not provide qualitative data (*n* = 53*)
Age at baseline (years)	66.5 (12.5)	61.4 (10.8)
Sex (male)	13 (52%)	32 (60%)
BMI (kg/m^2)	26.2 (4.3)	25.8 (4.6)
Histological type		
Squamous	6 (24%)	15 (22%)
Adenocarcinoma	17 (68%)	47 (70%)
Large cell	1 (4%)	3 (5%)
Other	0	2 (3%)
Unknown	1 (4%)	
EGFR or ALK mutation present	6 (24%)	11 (21%)
	n tested = 16	*n* tested = 43
Disease stage		
IA	1 (4%)	0
IB	1 (4%)	1 (2%)
IIIA	7 (28%)	15 (28%)
IIIB	2 (8%)	7 (13%)
IV	11 (44%)	27 (51%)
Recurrent	3 (12%)	3 (6%)
Metastases to brain, *n* (%)	2 (8%)	7 (13%)
Metastases to bone, *n* (%)	3 (12%)	7 (13%)
Time from diagnosis to study randomisation (days)	43 (22)	43 (26)
Time from diagnosis to interview completion	153 (134–170)	N/A

(days)		
Time from completion of 8-week program~~me~~ to interview (days)	35 (24–65)	N/A
ECOG-PS, patient-rated		
0	10 (40%)	14 (26%)
1	13 (52%)	34 (64%)
2	2 (8%)	5 (9%)
Clinical Frailty Scale score		
1 ‘very fit’	1 (4%)	2 (4%)
2 ‘well’	2 (8%)	6 (11%)
3 ‘managing well’	3 (12%)	3 (6%)
4 ‘vulnerable’	10 (40%)	26 (49%)
5 ‘mildly frail’	7 (28%)	14 (26%)
6 ‘moderately frail’	2 (8%)	2 (4%)
The Colinet comorbidity score	8 (7.00 to 9.00)	8 (7.00 to 9.00)
Chronic obstructive pulmonary disease	11 (44%)	27 (40%)
Time from randomisation to commencing Rx (days)	7 (20)	5 (15)
Treatment intent at randomisation		
Radical	13 (52%)	26 (49%)
Palliative	12 (48%)	27 (51%)
Intended/current anti-cancer treatment at baseline		
Radical chemoradiation	9 (36%)	21 (40%)
Palliative chemotherapy	4 (16%)	10 (19%)
Palliative chemotherapy and radiotherapy	1 (4%)	7 (13%)
Targeted therapy	2 (8%)	6 (11%)
Systemic clinical trial treatment	2 (8%)	3 (6%)

Radical radiotherapy	2 (8%)	2 (4%)
Stereotactic radiotherapy	2 (8%)	2 (4%)
Palliative radiotherapy	3 (12%)	0
Palliative radiotherapy and targeted therapy	0	1 (2%)
Induction chemotherapy and surgical resection	0	1 (2%)
Treatment to metastatic sites		
Resection of cerebral metastasis	2 (8%)	1 (2%)
Palliative radiotherapy to bone	1 (4%)	3 (6%)
Smoking history		
Never smoker	5 (20%)	9 (17%)
Ex-smoker	13 (52%)	31 (59%)
Current smoker	7 (28%)	13 (25%)
Smoking history pack years	38.75 (29.50–52.50)	30.00 (18.00–45.00)
Social situation		
Home alone independent	6 (24%)	5 (9%)
Home with family	19 (76%)	45 (85%)
Rural residential status	5 (20%)	21 (31%)
Employment status		
Working (full or part-time)	2 (8%)	5 (9%)
Temporary/permanent sick leave	2 (8%)	13 (24%)
Not employed/taking time off	4 (16%)	4 (8%)
Retired	17 (68%)	21 (40%)
Highest level of education		
Finished primary		

schooling	3 (12%)	4 (8%)
Some secondary or high school	8 (32%)	18 (34%)
Completed secondary or high school	7 (28%)	7 (13%)
Some trade, community or TAFE college	1 (4%)	1 (2%)
Completed trade, community or TAFE college	2 (8%)	4 (8%)
Some university	1 (4%)	3 (6%)
Completed bachelor’s degree	1 (4%)	9 (17%)
Completed masters or PhD degree	2 (8%)	2 (4%)
Deceased at 6 months	2 (8%)	14 (26%) AQ5
Values are mean (SD), median (IQR) or number (percentage)		
*Fourteen RCT participants did not provide any follow-up data, frequently due to death, and were only included in analyses of the primary outcome		
The Colinet comorbidity score means score ranging between 0 and 20 including tobacco consumption (7 points), diabetes mellitus (5 points), renal insufficiency (4 points) and 1 point for each of respiratory, cardiovascular and neoplastic comorbidities and alcoholism [36]		
ALK anaplastic lymphoma kinase, *chemoRT* chemoradiotherapy, *ECOG-PS* Eastern Co-operative Oncology Group Performance Status (patient-rated performance status 0 = fully active, 1 = active but can only carry out light work, 2 = resting in bed less than < 50% of the day) [29], *EGFR* epidermal growth factor receptor, *Rx* treatment		

Views and experiences of program~~me~~ participation

Six main themes arose regarding the participant’s views and experiences of programme involvement (additional quotes in Table 4). The results sections which follow provide details regarding the number of participants whose responses were included in each theme as some participants did not answer all questions.

Table 4

Views and experiences of programme participation, participant quotes

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1. Theme: The perceived physical and mental health benefits of the program~~me~~	
Codes: Can you tell me what your impression of the home-based exercise program~~me~~ and symptom management phone calls was? What are the benefits of physical activity or exercise in your mind for people diagnosed with lung cancer?	
Motivation through the cancer journey	‘I am bad at exercise programs at any sort of time a um er and particularly after treatment it was difficult to get motivated, and it was a really good thing to have.’ (73) ‘hope for the future’ (39) ‘being an ex-smoker and being aware that I still miss the smoking, exercising helps you be aware of um um the health of your lungs um which helps to motivate you to keep them healthy.’ (73)
Improved symptoms	‘You feel better after you have done the exercise….I feel that it helps you get to be able to do more things, lead a more normal life. It makes you feel a little bit healthier, um It takes away the feeling of, um, um, sickness, you know, you do not feel it to such an extent.’ (83) ‘But I did find that you know um getting up and doing the exercise um would get rid of any of the cancer sort of symptoms so to speak, so if I was feeling tired and not bothered then just exercising and walking helps get rid of that you know.’ (73)
Better prepared for future challenges	‘It was vital to me. And I really think that if I had not had the exercises I would not have been well enough ... I think it got me fit enough to face up to doing the surgery. I had to have tests done to make sure I was fit enough and that proved to be okay and they went ahead and did the surgery.’ (29) ‘Well, hopefully it will enable you to cope better I suppose if you start off a little bit stronger and a little bit fitter. So when you get ill, sick, you may be able to cope better…’(49)
Improved mental health	‘Oh the, the benefits, um, for me is taking, taking me mind off, um, what’s goin’ on, um and not thinking what’s going to happen down the track and in 5, 6, 7, 8 months, am I going to pull through this?’ (84)
Prevention of boredom	‘It helps you… It helps me from being bored. You know, like there is nothing on television, I have nothing to do, I cannot do things because my back is killing me, [so] do the exercises.’ (47)
Uncertainty regarding programme benefits	‘I do not know [if the exercise program helped]. Not sure about that one you know because, still I am taking tablets and things like that too… Like for example, recently I got some morphine tablets maybe that’s why it changed everything too, you know what I mean?’ (82).
2. Theme: Most valuable programme aspects	
Codes: During the programme, you were contacted by a physiotherapist and a nurse—were there other health professionals that you would have liked to have had contact with in addition to or instead of the physio and nurse?	

Were the programme physio- and nurse consultations available at the right time or would they have been better at another time? What were the most and least valuable aspects of participating in the study?	
Benefits of the programme structure	‘I think the most valuable is, if I did have a plan an access for me. I can follow it. Maybe I not do so much exercise if there is no, if not this program. So this program is a very good guidance for me.’ (39)
Programme exercise content	‘Um, I enjoyed, I enjoy walking so that was a big part of the, the program so, um, you know, that that was, um, something that I enjoyed to do anyway, it wasn’t a big chore to have to do it…’ (92)
Support from programme staff	‘I think just having the ahh the people, you know someone there who’s you know sort of continually supporting you with things like that. I think that’s really important um you know you have got your family support and everything else but when you are having outsiders that show that they sort of give a bit of a shit but that does make it you know, the motivation is there a bit more too you know, and you are doing it for the right reasons.’ (33)
Improved physical and mental strength	‘But then I thought when I did start it I did, I must say I felt a lot better. I felt stronger and even mentally you think, just think maybe this will help you down the track.’ (51).
Timing of programme in relation to treatment	‘I do not think there was anything that wasn’t valuable. I am just sorry I could not do it absolutely properly, that’s all. So I thought, for me, it would have been better for me to start later, rather than doing it while I was doing the chemo and going through that time.’ (83).
Desire for further feedback regarding progress	‘No just … you know how things were going compared to the beginning…but I just would have thought they would have said you know ‘you kept your strength up’ or ‘you did or you did that’ um but that did not happen so.’ (36)
3. Theme: Enablers of programme participation	
Codes: What were the thoughts of your family/friends on you undertaking the exercise programme? What factors enabled you to undertake the home exercise programme? If the exercise programme had been run in the hospital, rather than at home, do you feel you would have been able to undertake the program? Did you feel supported and able to be guided with your exercises by the physiotherapist? What are the main factors that enable you to be active at the moment? Can you tell me what your impression of the nurse phone calls was? What did you find valuable/not valuable in regard to the nursing phone call?	
Physiotherapy home visits	‘But then when um (the physiotherapist) came out to my place and we went through the whole thing again and ahh everything else, that gave me the confidence to be able to do it because she and I went through it and you know made sure that I was doing it right and all that sort of stuff, that was really good.’ (24) ‘it made it possible for me to do it because it was tailored to what um, what I had available um, you know [the physio] designed it around ok you have got a chair you can use in that

	exercise use a door frame or a wall for this one…’ (73)
Support to progress exercise	‘Oh, yes definitely. You know she’s encouraged me uh, to sort of increase them a bit if I could, and that’s what we have done. Oh, yes she’s been very good.’ (49)
Support to regress exercise	‘Yes yes and even to the point where at one stage we cut back on the number of repetitions we did because that was after I’d been sick and I was struggling to get things done. So we cut back on them.’ (24)
Telephone follow-up	‘Because she worry about me a lot and thinking about me, ring up me every little while and I am really happy and she really er try to help me how she can of course.’ (40).
Partnership between clinician and patient	‘Yes, yes, yes she was very accommodating, um and she was definitely there in my corner if I needed help, additional help, or you know, she, she was very good.’ (92)
Nursing symptom self-management support	‘Very much so. I think it’s because you, um you have got someone to talk to about it. Like I mean um, she wasn’t the one treating me so I could say they did this, this and this.’ (51)
The nurse was a source of information	‘Oh she was very, very full of information, helpful information and encouragement. No no she was, there were days when I was feeling down you know and, but, she was there to guide me, she was there to help me.’ (23)
Nursing symptom management support during exercise	‘Oh she always been asking me how you go, what you feel and things like that you know what I mean? Yeah, yeah, no, she was interested in the, er, what’s was going on, you know?’ (82)
4. Theme: Intervention package enablers of exercise adherence	
Codes: Did you watch the DVD provided within this study? If yes—how did you find it? Is there anything you would have liked included? If no—why? How would you have preferred to receive the information on exercise? A daily text message reminder was sent to exercise—how did you find this? How did you find the patient diary and Fitbit device you used to record what you were doing?	
Exercise diary	‘…it’s like, you know, recording what you have done and you say, ‘bloody hell I can do things you know, I am not hopeless yet you know’. So I think for me I found it very encouraging… and um ahh but after you doing it for a couple of weeks you say, ‘oh gee I did this, gee you know, I am doing alright’. (68) ‘I do not write… Oh, I just look eh at it and eh it was all of those numbers and everything and I usually tell the physio what I did and what I did not and all that.’ (43)
Fitbit Zip® activity tracker	‘Yes it has been good to compare. On the days when I am not feeling well I might only do 4–5 thousand and the days when I am feeling ok and even now just yesterday I did 9, 300 or something.’ (25) ‘I mean like I use my smart phone so it tells me how many

	how far I have walked. I I look up the heart health, the health check app on my phone all the time.' (24)
Exercise DVD	' Cause there was 4 or 5, maybe even 6 exercises that I was shown at the time. 'Ok um how do I do that?' Ok I'd put the video on and watch it and I [it] gave me a reminder.' (84) 'No I did not actually [watch the DVD] because [the physiotherapist] was coming over and showing me everything and doing the exercises with me.' (25) 'No, only because my [DVD] machine is not hooked up and we cannot seem to hook it up properly.' (83)
5. Theme: Challenges and barriers to exercise	
Codes: What were the challenges with undertaking the home exercise program? What are the main factors that prevent you from being physically active? Were there times you were not sure whether it was safe to exercise? If so, can you tell me a little more about this? How could we have reduced this uncertainty?	
Symptom exacerbation—cancer-related fatigue	'It wasn't difficult but sometimes you are not feeling 100% you know. You have not got the energy to do it. Umm well during the cancer treatment yeah I had no energy.' (68)
Lack of motivation	'When you are tired it's very hard to motivate to get out and to do the exercises.' (24)
Lack of acceptance	'Um that I've had breast cancer three times and I have found that my best way of getting over it was to put it right out of my mind and pretend that I wasn't sick….. It was just me. I felt it was more a mental issue that I did not want to do them rather than anything physical.' (29)
Adverse weather conditions	'…so if the weather's alright you just go for a stroll or if it's not alright then you do not bother because you know you are not going to be feeling real flash when you get back if it's raining or too hot.' (78)
Unplanned hospital admissions and demanding treatment schedules	'I actually got put into hospital with a pretty high temperature and that meant that I did not do the exercises for a week and then having to start them again you know you do not realise that in one week you can lose so much…' (24) 'Yeah, well no you are there every day for 6 weeks and um yeah you are not, you are not in charge of your day..' (71) 'Um, I had to go in for some treatment yesterday and, um. Yes, so um so that's been a little bit squew-iff actually at the moment, it's not very consistent.' (92)
6. Theme: Managing symptoms during exercise	
Code: Did your confidence to manage symptoms change as a result of participating in this study?	
Symptom-support perceived as caring	'It does, you think people care…. to ring up and find out how are you, people care, well I should do the right thing…' (57) 'I think if I wasn't in the trial I'd be quite miserable.' (51)

The program~~me~~ was perceived as resulting in physical and mental health benefits

The majority of participants (19/21) felt strongly that the program~~me~~ was helpful. The program~~me~~ helped motivate participants to be healthy throughout their cancer journey. Participants reported feeling physically and psychologically stronger. These health benefits led some participants to feel better prepared for the challenges ahead, including future treatments, possible disease progression, participating in recreational activities such as car racing and undertaking daily domestic and community activities. The program~~me~~ also allayed boredom and gave a sense of purpose for participants who had nothing to do, were socially isolated or could not participate in their usual activities because of their health. The program~~me~~ gave participants something to move on with and kept their minds busy. Several participants noted that the program~~me~~ involved research that would help others.

> I well I got through it [the program] alright… I've actually stepped it up a bit from when I first started. You know a bit more intense and uh, heavier weights and uh, doing longer and all that sort of thing. I can certainly get out of the bath a lot easier now (laughing). Yeah, so I'm a little bit stronger than when I started I think. (49)

> I feel my inside better, mentally better and my day is a bright day every day. (68)

Only two participants were unsure if the program~~me~~ was helpful. One reported not knowing because program~~me~~ staff had not provided her with outcomes. The other was unsure because his medications had also altered during his participation.

Most valuable program~~me~~ aspects

Perspectives on the most valued aspect of participation (*n* = 23) were diverse. Generally, participants felt the home-based design enabled the program~~me~~ to fit around often demanding treatment schedules or poor weather conditions. The inclusion of aerobic exercise content was most valued by some. Walking was commonly described as a preferred form of exercise that had been previously enjoyed, could be incorporated into daily routines and provided increased opportunities to socialise. The care and support provided during the program~~me~~ was both valued and a motivator to participate, as were the health benefits reported.

> That it focuses on A) do your exercises, because this is part of your whole treatment. I treat it as the same as going for the radiation or going for chemo or just going to see my GP or whatever, it’s all part of the parcel of the bigger picture. (24)

The only least valued aspect reported (*n* = 1) was program~~me~~ timing during radical chemoradiotherapy. Most participants (*n* = 19) were satisfied with the information received from the physiotherapist, with one participant suggesting more information about her exercise progress would have been welcomed.

Enablers of program~~me~~ participation

The experience of support and guidance from the physiotherapist was overwhelmingly positive, particularly during home visits. Participants felt prescribed exercises were achievable as they were individually tailored, monitored and modified as required and did not require specialised equipment. Participants felt the physiotherapist facilitated safe exercise performance. Demonstration and oversight of the program~~me~~ gave participant’s confidence that they were performing exercises correctly. This support and guidance was valued particularly when exercise was progressed and also when exercise needed to be reduced, during times of increased symptoms or following unplanned hospital admissions. Participants felt their wellbeing was a partnership, with the physiotherapist on their side. Program~~me~~ involvement gave participants the sense that exercise was expected of them and one participant reported feeling guilty if they were not adherent.

> Well when the physio said well how many sets could you do. Well I would not know how many sets to do so she guided me. And modified them. (25)

Home location was also an enabler. Participants were asked whether a hospital-based program~~me~~ would have been preferred or possible for them. Twelve of 14 respondents selected home as their preferred site of intervention for reasons including the time, costs and energy expended getting to hospital. Home also enabled a more flexible routine, allowing exercise to be balanced with rest or arranged around how they were feeling. Participants, who indicated that hospital would have been possible, indicated that daily would have been difficult and preference would have been to fit exercise in around other appointments for treatment or review. The overwhelming view was that home enabled the inclusion of daily exercise, with indications that a hospital program~~me~~ would have meant many sessions were missed.

> Yes (possible), but it's a little bit too hard to get there every day… (43)

Support and guidance to manage symptoms, provided during telephone contact from the nurse, was viewed positively. Participants felt supported by the information provided and when their questions were answered. The nurse's interest in the participant's exercise experience, including how the program~~me~~ was tolerated, was perceived as supportive.

Most participants reported family and friends as supportive, encouraging them to undertake the program~~me~~. Several participants reported family members or friends were undertaking the program with them. Two participants reported their family were supportive but also concerned. Only four participants had not discussed the program with their family and one reported his carer was not supportive. Several participants had family members who were health professionals. Having future family events to attend was cited as an exercise motivator.

> You have to put yourself in control to do what you have to do, to have, you know to have results, good results. No, I like to keep myself like I am because I expecting grandson go to marry and I expecting to be there. You know, I like to be there. (40)

Intervention package enablers of exercise adherence

Most participants (*n* = 17) found the daily text messages a useful reminder to exercise, a personal motivation, and felt they demonstrated caring from program~~me~~ staff.

> Oh yes. Well a, that was good. Because I forgot [and] I don't know [I] forgot it [to exercise]. You know sometimes you want to feel a bit slack and you think oh, I got a message (laughing) I

> better hurry up and do it, move it. (23)

Several participants ($n = 3$) did not mind receiving the text messages and however reported they were not useful as they were doing the exercises regardless.

> Oh (laughing) well, I suppose they [text messages] would have been [useful] if I hadn't wanted to do the exercises. But I was doing them anyway so, I suppose it was a reminder but eh I didn't really need them. (49)

The exercise diary was valued by most participants ($n = 17$), to record PA and health information (symptoms and side effects), and created motivation and adherence to exercise. Some participants ($n = 5$) did not find the exercise diary useful for reasons including an inability to write and losing the diary, and in three cases, the diary offered no additional benefit because the participants felt familiar with the exercise program~~me~~ and the dosage prescribed.

Thirteen participants found the Fitbit Zip® activity tracker useful for recording information about their PA levels and sometimes for evaluating the effect of symptoms on their PA levels. Several participants ($n = 3$) felt the device was unnecessary, in two cases, because they preferred to use their own technology and one participant had no interest in using this type of technology.

There were mixed responses to the programme DVD. Only four participants viewed the DVD and reported it provided some general learning about exercise and a reminder of how to perform the exercise program~~me~~. However, 21 participants did not view the exercise DVD, either believing it to be not necessary given other resources or because of a lack of interest.

Challenges and barriers to exercise

By far, the most common challenge to completing the program~~me~~ related to increased symptoms included fatigue, lack of energy, dyspnoea, dizziness, diarrhoea, nausea, poor appetite, coughing, toe infections and pain.

> I couldn't breathe and ah and so because I couldn't breathe it all stopped. It was the breathing that did it so when you can't breathe you can't do anything, you can't walk you're quite sedentary. (51)

A range of intrinsic factors were also noted as challenges including lack of motivation, particularly around performing the resistance exercises, and prioritising other tasks ahead of exercise. One participant reflected that a lack of willingness to accept her current situation was a challenge. Weather conditions, such as extreme heat or cold, wind and rain reduced adherence to the walking component of the programme. Unplanned hospital admissions, medical appointments and busy treatment schedules impacted on participants’ ability to undertake the programme or maintain activity levels.

Given the program~~me~~ was largely unsupervised, participants were asked if there were times when they were not sure whether it was safe to exercise. Respondents (*n* = 18) did not feeling unsafe exercising, 13 felt it was always safe to exercise and five indicated that there were times when they were unsure, such as during heightened symptoms, and did not exercise during those periods. No serious adverse events related to the program~~me~~ occurred.

Managing symptoms whilst exercising

AQ7

Participants reflected on their experiences of managing their symptoms. Thirteen of the 19 participants asked about the symptom management support provided by the nurse reported a positive change in their confidence to manage their symptoms. Three participants responded their confidence was unchanged and one was unsure as he had started the program~~me~~ prior to chemotherapy commencement. Areas of improvement discussed by those who responded positively included the ability to identify and deal with symptoms, including shortness of breath and having a better sense of what to expect. The support provided during the symptom management telephone calls gave participants the feeling that someone cared.

> …it gave me confidence that what um that my symptoms were symptoms and not me being stupid or you know and um, yeh it helped me identify symptoms and how how to um to deal with them yep. (73)

Discussion

In this novel study, we investigated the views and experiences of participants involved in a home-based rehabilitation program~~me~~ commenced during treatment for inoperable lung cancer. Our program~~me~~ was highly acceptable, with most participants reporting multiple benefits including the following: improvements in strength, fitness and motivation; being given a sense of purpose which prevented boredom; feeling better prepared for future challenges; and an improved ability to manage symptoms. Most participants reported the exercise program~~me~~ to be achievable and valued the individualised prescription and monitoring support provided by experienced physiotherapists and home-based setting. Self-efficacy for achieving behavioural change is crucial in predicting adherence and subsequent program~~me~~ outcomes [37]. Our findings are echoed in operable NSCLC where participants reported high acceptability of a post-operative home-based intervention, which significantly improved cancer-related fatigue [38].

A key component of program~~me~~ feasibility is adherence, the proportion of prescribed exercise training that is completed. Adherence in our study was 65%, below the level deemed optimal for improving outcomes in pulmonary rehabilitation program~~me~~s [39], but high given the overall health status of participants with inoperable disease receiving anti-cancer therapies. Our adherence is significantly higher than the 9% previously reported in a lung cancer population at chemotherapy commencement, exercising at home, of similar age, gender and disease stage [40]. The social benefits of connecting with people in similar situations, during hospital-based exercise sessions, was previously found to be a major factor contributing to poor home exercise program~~me~~ adherence [40], but this was not the case in our study. Of note, 67% of Adamson et al.'s study participants lived alone, compared with 24% in our study. Aware that our program~~me~~ lacked the social benefits of supervised group exercise, we aimed to reduce isolation associated with home exercise by encouraging program~~me~~ involvement from family and friends and through regular contact from program~~me~~ staff. Providing support to manage symptoms during exercise is also important, given previous reports that symptoms and fear of exacerbation are significant barriers to exercise participation [41, 42]. This additional component of our intervention, along with the increased social support at home, behaviour change strategies, use of activity trackers and exercise text message reminders, may have resulted in our improved adherence. Our adherence fell well below reported adherence in the operable population (93%) [38], likely due to differences in disease stage and management, as 78% of participants had early-stage disease and all were managed surgically. The indoor nature of the exercise, using the Nintendo Wii Fit Plus, also removed the barrier to exercise created by poor weather conditions [38].

Knowledge regarding patient perceived PA enablers and barriers in lung cancer is growing. Many enablers and challenges to participating in our program~~me~~ support existing literature. Individualised exercise prescription, guidance from experienced program~~me~~ staff and supportive family enabled participants to exercise. Aerobic exercise was enabled as walking was a familiar and enjoyable form of exercise [23, 43]. Challenges to exercise participation were periods of symptom exacerbation, adverse weather conditions, reduced motivation, prioritising other tasks ahead of exercise, unplanned hospital admissions and demanding treatment schedules [18, 23]. Our study adds to these findings as one of few to report the experiences of exercise participation during treatment for lung cancer and highlights patient-derived features enabling successful home-based rehabilitation. Evidence suggests hospital-based rehabilitation program~~me~~s result in greater benefits than unsupervised home-based programmes: however, this research has largely been conducted in breast, colorectal and prostate cancer populations [4]. In contrast to previous findings, our home-based exercise was reported to be highly acceptable, safe and result in numerous benefits for people with inoperable lung cancer, when coupled with support to self-manage symptoms, regular contact from program~~me~~ staff, social support from family and friends, exercise text message reminders and use of activity trackers.

Study strengths and limitations

Few studies have reported qualitative data regarding the patient experience of rehabilitation participation during lung cancer treatment, particularly in those with inoperable disease. As such, this study provides valuable data which can be used to inform the design of future trials and guide clinical practice recommendations. Several study limitations should also be acknowledged. There is potential for bias given several participants declined or were unable to participate in the interviews resulting in 55% of the RCT sample providing information. Our sample may represent those who found the intervention more acceptable or derived the greatest benefits, thus limiting the generalisability of our findings. However, exercise adherence in our interviewed sample was only slightly higher than for all IG participants. Interviews were conducted individually by telephone and results may have differed if face-to-face interviews or focus groups were utilised. The varied duration between completing the 8-week program~~me~~ and conducting the interview may have influenced participant program~~me~~ recall. We were unable to interview participants who withdrew. Included participant's appreciation of the support provided to them may have resulted in lower reports of negative program~~me~~ experiences.

Conclusion

This home-based rehabilitation program~~me~~ was well accepted by participants with inoperable lung cancer undergoing active treatment, highlighting the need to improve access to supportive care services, including exercise advice and symptom management support, for this under-served population. Importantly, no serious adverse events occurred and participants reported feeling safe exercising at home. The program~~me~~ setting, content and delivery were highly acceptable to most participants. Strategies to enable exercise adherence, such as the use of inexpensive activity monitors and automated text message exercise reminders, were well received. The study was feasible to deliver in the home setting. Future research should consider methods to strengthen exercise adherence, such as providing alternative indoor exercise plans to remove barriers created by poor weather conditions, digital educational materials and remote monitoring of activity for participants capable of utilising these newer technologies [44, 45]. Further work is required to determine if a mixed-setting approach is feasible in this population, predominantly home-based with flexible supervised hospital sessions as required to enhance adherence, confidence and motivation and ensure fidelity of exercise. Incorporating emerging pulmonary telerehabilitation technologies into future programme design, such as virtual exercise groups [46], is also worthy of investigation to increase the social benefits of participation whilst still allowing exercise to be home-based.

Publisher's note

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Compliance with ethical standards

Ethical approval All procedures performed were in accordance with the ethical standards of the Peter MacCallum Cancer Centre ethics committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors declare that they have no conflict of interest.

Electronic supplementary material

ESM 1

(DOCX 22 kb)

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