

Improving the delivery of physical activity services in lung cancer: a qualitative representation of the patient's perspective

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Abstract

Objective: To explore patient experiences of, and preferences for, physical activity after a lung cancer diagnosis. **Methods:** This was a qualitative study involving seven patients who had been treated for lung cancer within the previous two years. Participants attended a focus group interview. Conventional content analysis methodology was used to analyse the text by two independent researchers. **Results:** Eight major themes emerged from the data. These were: the influence of past lifestyle and chronic disease; the perceived benefits of physical activity; using physical activity to facilitate return to activities of daily living; the impact of symptoms, capacity and motivation; family and peer support; access to services; health professionals; and enjoyment of different types of physical activity. Patients suggested several factors that could improve their healthcare experience. These include access to exercise professionals particularly after cancer treatment; access to information about physical activity in different formats; supervision from health professionals and peer-support; and use of behaviour-change strategies to achieve sustainable increases in physical activity. **Conclusion:** Our results should be considered in the improvement of lung cancer care pathways as we strive to implement physical activity services into routine clinical care.

Key words: lung cancer; patient perspective; physical activity; exercise; implementation

Introduction

Lung cancer is a major challenge to global healthcare (Fitzmaurice et al., 2016). It was responsible for 36.4 million disability adjusted life years (DALYs) worldwide in 2015 (Fitzmaurice et al., 2016). Whilst most DALYs come from years of life lost, the high morbidity associated with lung cancer is a significant concern (Fitzmaurice et al., 2016). A third of patients attribute major impairment in their daily activities to having lung cancer (Sung et al., 2017). People with lung cancer experience debilitating symptoms such as fatigue, cough and dyspnoea, and decline in physical function after diagnosis (Sung et al., 2017, Granger et al., 2014). Most patients do not meet minimum recommended levels of physical activity for health (Rock et al., 2013) before, during or after cancer treatment (Granger et al., 2014, Stevinson et al., 2014, Coups et al., 2009). Beyond medical treatment, patients have unmet survivorship needs which are not consistently addressed in current practice (Granger, 2016, Sung et al., 2017).

There is unequivocal evidence for the benefits of physical activity for people with cancer (Schmitz et al., 2010). Historically evidence has come from breast, colon and prostate cancer (Rock et al., 2013), but recent growth of evidence specifically in lung cancer (Schmitz et al., 2010, Granger, 2016, Rock et al., 2013) supports the need for widespread implementation of physical activity services into routine lung cancer clinical care. Physical activity is associated with improvements in fitness, muscle strength and health-related quality of life (HRQoL); and a reduction in symptoms including fatigue, dyspnoea, and depression (Granger, 2016, Crandall et al., 2014, Granger et al., 2011). The strongest evidence is in the post-surgical setting (Crandall et al., 2014), with growing evidence before surgery and in the advanced stage of disease (Granger, 2016). Therefore, it is a concern that access to physical activity services are not commonly part of routine lung cancer care in most countries around the world (Dennett et al., 2016, Canestraro et al., 2013, Stevinson and Fox, 2005, Smith et al., 2017).

The barriers to implementing evidence regarding physical activity into lung cancer clinical practice were recently described (Granger et al., 2016, Granger et al., 2017). These include lack of available services, lack of clinician time and knowledge; and preclude patients with lung cancer from accessing information about physical activity or exercise training programs (Granger et al., 2017, Granger et al., 2016). This information provides an excellent platform to work with as we strive to establish physical activity services into routine care. However, the patient experience is vital to inform the design and implementation of new

services (Garratt et al., 2008), particularly to ensure maximum access, uptake, adherence and benefit. Qualitative methodologies are recognised as an effective way to capture the patient voice and allow in-depth understanding to inform service improvement in cancer care (Tsianakas et al., 2012). Therefore, the aim of this study was to explore patient experiences of, and preferences for, physical activity after a diagnosis of lung cancer. For this study, we were interested in any type of physical activity and did not restrict this to exercise training alone.

Methods

Setting

The focus group interviews were conducted at The University of Melbourne, Australia in a private room. Only the participants, the facilitator, and a scribe were present.

In the Australian healthcare setting patients with lung cancer are unlikely to have significant exposure to advice about physical activity or exercise training for their condition (Granger, 2016). Most patients with lung cancer receive physiotherapy if they are an inpatient in a hospital, for example to undergo thoracic surgery (Granger, 2016). However usual physiotherapy in this setting normally involves mobility assessment (for discharge) and prevention or treatment of post-operative complications following surgery (Granger, 2016) rather than interventions to increase physical activity levels following discharge or access to exercise programs (Granger, 2016). Following the hospital admission, most patients with lung cancer do not receive ongoing follow-up physiotherapy or access exercise programs (such as pulmonary rehabilitation) or exercise physiologists for their lung cancer condition (Granger, 2016, Cavalheri et al., 2013). This practice is not dissimilar to other countries (Kendall et al., 2017).

Design and theory

The methodological orientation and theory underpinning this study was conventional content analysis (Hsieh and Shannon, 2005). This approach was chosen to avoid using preconceived ideas/categories and allow coding to come directly from the data generated from participants themselves (Hsieh and Shannon, 2005). Focus group interviews were chosen to allow for conversation and a natural progression of ideas shared between the participants in the group.

Participants and data generation

Participants were recruited for this study from the community and were not restricted to certain hospitals. The study was advertised using two approaches: 1) invitations to potential participants were distributed by the Cancer Council Victoria to members of their support groups in email and written format; and 2) a newspaper advertisement in a state-wide public newspaper. Expressions of interest to participate were received, and screened for eligibility. The inclusion criteria for participation were: adults with a previous diagnosis of lung cancer, who had received treatment in Australia, and had sufficient English language skills. Eligible participants were invited to participate in one of two repeat focus groups. A semi-structured interview schedule was developed and used to guide the focus groups (Appendix 1). The focus groups were run in August and December 2015 for 78 minutes and 32 minutes respectively, and they ran until no new ideas emerged (at the discretion of the facilitator). The focus groups were audio-recorded and field notes were taken (by researcher MD). The focus group interviews were facilitated by a female PhD qualified academic physiotherapist (SP) who had experience in facilitating focus group interviews and she was not known to participants. At the beginning of each focus group interview, the participants were provided with background information on the facilitator's expertise and her involvement in this study as a researcher.

Data analysis

The focus group recordings were de-identified, transcribed verbatim and independently crosschecked by a second researcher (MD and NL). Participant quotations were transcribed in a non-identifiable manner. Data from the two focus groups were analysed together. Themes were derived from the data. This was performed using conventional content analysis methodology which comes from a naturalistic paradigm (Hsieh and Shannon, 2005). In conventional content analysis, coding categories are derived directly from the text data (Hsieh and Shannon, 2005). This type of analysis was chosen as it allows information to be obtained directly from the participants without the researchers imposing preconceived ideas, categories or theoretical perspectives (Hsieh and Shannon, 2005). This was particularly important in the case of these focus groups about physical activity, where the researchers could be coming from a biased view towards the importance of physical activity. Two researchers independently performed the analysis (CG and SP). As per conventional content analysis methodology, text data were read word-by-word to derive codes to key thoughts and

ideas (Hsieh and Shannon, 2005). This formed the initial coding scheme (Hsieh and Shannon, 2005). Codes were then sorted into categories based on the relationship between codes, and grouped into meaningful clusters (Hsieh and Shannon, 2005). The final overall themes and sub-themes were developed by the independent researchers, cross-checked between them, refined and grouped until consensus was obtained. No software programs were used for analyses.

Ethical Considerations

The study was conducted and reported according to the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007). Ethical approval was obtained from the University of Melbourne Human Research Ethics Committee (Project Number: 1442666.1). All participants provided written informed consent, including consent to publish de-identified participant level data prior to participation in the study.

Results

Between July and December 2015, 16 potential participants expressed interest in participating in the study. All were eligible for inclusion. Seven of the 16 participants consented to the study, the remaining nine people subsequently declined due to the time commitment or travel required. Following consent, there were no drop outs or withdrawals. There were five female and two male participants, ranging from 60 to 72 years of age. All participants had completed treatment for lung cancer within the previous two years. All participants lived at home and could walk independently. Two participants were still working.

Eight major themes and 27 sub-themes emerged from the data with regards to the patient experiences of, and preferences for, physical activity after diagnosis. Major themes were: the influence of past lifestyle and chronic disease; the perceived benefits of exercise after a lung cancer diagnosis; using exercise to facilitate return to activities of daily living (ADLs); the impact of symptoms, capacity and motivation; family and peer support; access to services; health professionals; and enjoyment of different types of physical activity. These themes are described below and summarised in table 1 and figure 1. Sub-themes are highlighted in bold. Participant quotations supporting each theme are provided in table 1.

[Table 1 and Figure 1 near here]

Theme 1: the influence of past lifestyle and chronic disease

Participants felt they **lacked fitness** prior to diagnosis. They described a long history of **sedentary behaviour**, which was promoted by their enjoyment and participation in sedentary-based hobbies. Some participants explained that they had been smokers in the past and blamed their poor health on their smoking. They experienced **self-blame**, low self-esteem and stigma associated with lung cancer and smoking. Participants described the impact that other **chronic diseases** had on their lifestyle. Chronic diseases were predominately respiratory and cardiovascular, which many participants believed were due to smoking. Due to these pre-existing chronic diseases, some people had experienced the Australian healthcare system before being diagnosed with cancer. This included being hospitalised, having appointments with medical specialists, and being sent for various medical investigations. Some participants had previously been involved in exercise programs prior to diagnosis for the management of other conditions such as cardiac rehabilitation following cardiac surgery.

Theme 2: The perceived benefits of physical activity after a lung cancer diagnosis

Some participants believed they had **benefited from physical activity** after their cancer diagnosis and viewed physical activity as important to keep fit, strong and healthy. They also believed that lack of physical activity could result in their health deteriorating. The belief that physical activity was worthwhile and beneficial was highlighted as a motivational factor to keep active and exercising. One of the key reasons they performed physical activity was to counteract the feeling of restlessness, to occupy time and to **improve their mental health**. Physical activity gave them something to do and was a good distraction, especially early after diagnosis when they were suffering from shock and while waiting for treatment to begin.

Theme 3: Using physical activity to facilitate return to activities of daily living (ADLs)

Physical activity was a strategy to promote recovery. Participants kept active to **keep up their usual life and ADLs**. Some participants felt it was important to continue to participate in their usual, enjoyable activities given their poor prognosis. Participants felt their own participation in physical activity was something that they could control. **Activities of daily living** were viewed by participants as a type of physical activity. These included daily chores, gardening and walking for transport. People living alone explained that they had to keep up

these activities because there was no one else to do them. However, participants also noted that to keep up their ADLs they needed to adapt the task based on their physical ability. Participants talked about managing ADLs by breaking up tasks and taking frequent breaks or “pacing”.

Theme 4: The impact of symptoms, capacity and motivation

Symptoms including breathlessness, fatigue, lack of sleep and pain impacted participants’ ability to perform physical activity. Depression was raised as a harmful symptom that was aggravated by cancer treatment and made it hard to be motivated to be active. Physical activity was particularly difficult **during chemotherapy** when symptoms were at their worst and immediately after diagnosis (before treatment) due to the shock of diagnosis and the competing time priorities. To manage symptoms, participants highlighted the importance of breaking up activity with rests, particularly when suffering from fatigue. The inability to do certain activities was described as a **frustration**, particularly walking up stairs and hills. Whilst symptoms were a barrier to physical activity, participants also described that they understood physical activity to be a strategy to help **improve their symptoms**. The cold **weather** was a barrier to physical activity due to the aggravation of symptoms. **Self-pacing, monitoring and progression** were strategies participants used to keep active. This included progressing their own exercise slowly, breaking down tasks to be achievable, monitoring their progress through external feedback with devices such as activity trackers, and celebrating small achievements. **Fear** of physical activity was a problem. Participants described not doing physical activity because they felt they were not brave enough or they were concerned about the risks, including ‘overdoing it’ or overexerting themselves.

Theme 5: Family and peer support

Family and carers were predominantly described as restricting peoples’ participation in physical activity. Participants found it hard to overcome advice and wishes of their family/carers for them to rest, and they found this required significant energy to overcome. Some participants felt socially isolated and others felt they had no one to talk to who would understand what they were going through. Some participants described positive experiences of exercising in a group program. This created a sense of belonging and gave them **peer support**. The routine and responsibility to ‘turn-up’ at a set time for the group was a helpful motivating factor for adherence.

Theme 6: Access to services

Participants highlighted many practical barriers to physical activity. **Lack of time** was one such barrier. They felt that for physical activity to be sustainable it needed to easily fit into their daily schedule and be at a set time. Access to services was another barrier. Participants felt they received very good continuation of medical care but they did not receive sufficient **follow-up care** regarding physical activity, exercise or lifestyle after treatment. Some people described available exercise services in their local area, yet others expressed frustration and anger that they did not have similar access. **Location** was a limiting factor to access services given transport restrictions for some patients. The **cost** to pay for private services, such as a gym membership, was a barrier to exercise.

Theme 7: Health professionals

There was a desire for **health professionals** to provide support around physical activity, as a strategy to allow participants to safely and effectively exercise, and by means of enhancing motivation. Exercising in a hospital setting was seen as a safe option that could counteract their fear of exercise. Participants viewed the **time** after treatment, or the time once the full treatment plan had been established, as being the best time to start exercise. Immediately after diagnosis patients felt overwhelmed and overloaded with medical information.

There were conflicting opinions regarding the best **methods of delivering information** about exercise. In general, participants felt that they received too much general written information. Participants commented that they could not use and / or disliked computers and smart phones, and felt a combination of approaches were required to meet the needs of everyone. Participants expressed a desire to be able to telephone someone for support when needed. They also wished to have resources available to go back to if they had forgotten the verbal information. **Group-based** exercise programs were preferred over exercising alone. Participants believed group-based services provided an opportunity for peer support and to share knowledge.

Participants felt that they knew they needed to perform physical activity, but lacked knowledge of why and how. Knowledge alone was not enough for them to change their **physical activity behaviour**. They wished for guidance on how to change their behaviour and sustain it. They believed that external motivation was a key factor. Some participants described positive experiences with using external feedback such as activity trackers to

motivate them, but they acknowledged that everyone needs individualised motivation and personal goals that are meaningful to them.

Theme 8: Enjoyment of different types of physical activity

There were contrasting opinions regarding the enjoyment of different types of physical activity. Overall walking was the most favourable activity, yet not all participants viewed walking as exercise. Gymnasiums, treadmills, weights and jogging were raised as being enjoyed by some participants and disliked by others. Generally, participants enjoyed activities and exercises that they felt they were good at and had performed pre-diagnosis. Personalised exercises tailored to the individual were sought after.

Discussion

The patient experience is extremely important in the assessment and development of quality healthcare interventions (Garratt et al., 2008). The lung cancer patient population have unmet survivorship needs which require attention (Granger, 2016, Sung et al., 2017). Our study focused specifically on the patient experience of physical activity after diagnosis of lung cancer due to the strong evidence regarding benefits (Rock et al., 2013) and the current rarity of physical activity services as part of routine clinical practice for these patients (Dennett et al., 2016, Canestraro et al., 2013, Stevinson and Fox, 2005). We identified factors which need addressing to improve the patient experience. Aspects suggested by patients were: increased access to health/exercise professionals particularly after treatment; access to physical activity information in multiple different formats (such as paper, electronic, face-to-face, and telephone support); availability of group-based programs with supervision from health professionals and peer support; and utilisation of behavioural change strategies to help achieve sustainable increases in physical activity. Incorporating these factors into routine clinical practice will likely enhance the patient's ability to exercise and translate to improved outcomes. Our study also highlighted barriers to physical activity including: fear; lack of self-confidence; the impact of symptoms especially during treatment; misguided (but well-intentioned) support from carers promoting rest; and a lack of availability of physical activity services. These results provide valuable clinical information to guide the design and improvement of services.

In our study participants expressed a desire to perform physical activity. Motivating factors included their experience of benefits from physical activity, the ability to use physical

activity as a mental distraction, and the desire to use physical activity as a means to maintain ‘normality’ in life. These findings are generally consistent with prior work in lung cancer and palliative care populations reporting the majority of patients are interested in and feel able to participate in exercise programs (Lowe et al., 2010) and a desire for more support (Smith et al., 2017). One important, relatively novel, finding in our study was the identification that patients desire assistance with behavioural change. A compelling patient quote describes the experience of one patient who has been advised to exercise and despite knowing he needs to, he reports being unable to change his behaviour. Changing behaviour is especially difficult for patients who have had a lifelong history of sedentary behaviour. Behavioural change interventions are effective in a variety of chronic health conditions to increase physical activity levels (O’Halloran et al., 2014, Avery et al., 2015), including populations with breast cancer (Bluethmann et al., 2015). A recent systematic review in cardiovascular disease demonstrated that mobile wireless devices used to deliver self-management interventions successfully improved physical activity levels (Pfaeffli Dale et al., 2016). Changing behaviour is not an easy task and many cancer trials delivering physical activity interventions achieve improvements in a variety of outcomes including fitness, but not in physical activity behaviour (Bourke et al., 2014, Hudis and Jones, 2014). In line with pulmonary rehabilitation recommendations (Spruit et al., 2013), self-management strategies to assist patients to sustainably change physical activity behaviour and maximise self-efficacy are required. There are several lung cancer studies in progress currently, which incorporate behavioural change techniques alongside traditional exercise training (Edbrooke et al., 2017, Peddle-McIntyre et al., 2017) and we wait with anticipation for the results. It is likely that physical activity services will be most effective if they include an inter-disciplinary approach. For example, a service could include exercise training/advice from physiotherapists, combined with lifestyle behavioural change techniques from psychologists, and symptom control from nurse specialists.

The ‘one size does not fit all’ message is clear. Cancer survivors are diverse and preferences for physical activity are similarly varied. Our results are consistent with prior work encouraging individualised prescription for people with cancer (Hudis and Jones, 2014, Granger, 2016). Our patients had contrasting views on the types of physical activity they preferred and the ways in which information should be delivered. A physical activity service with opt ins and outs, and one that can be adapted depending on the preferences and needs for the individual person is required. An interesting finding in our study was the preference for

group-based programs. This is in contrast to the advanced cancer literature with several studies reporting preferences for home-based programs (Lowe et al., 2010, Hoffman and Brintnall, 2017). It may be that subgroups of patients with advanced disease prefer home over hospital settings, as their medical appointments and symptoms may have a higher burden than those with localised disease. However, exercise trials that have involved a combination of hospital and home-based exercise report poor adherence to the home component. Participants report a number of reasons for this – lack of social support at home; being unable to find the motivation to exercise; and a sense of accountability to other group members to attend hospital sessions despite symptoms (Adamsen et al., 2012). Our participants believed that the added benefits from group programs, such as social support and knowledge sharing with peers, was a favourable bonus. Therefore, service flexibility to accommodate patient preference in regards to exercise setting (i.e. home versus community) is likely to achieve the greatest uptake and ongoing adherence.

The role of carers to facilitate patients' behaviour change is vital. Our participants recalled that their family or carers often restricted their participation in physical activity and promoted rest. Treatment for cancer can be as impactful on carers as it is on patients (Simoneau et al., 2013). Family can have both positive and negative influences on patient's physical activity levels (Mas et al., 2015). Badger et al (2007) demonstrated that counselling along with self-managed exercise can reduce anxiety in patients with breast cancer and their caregivers (Badger et al., 2007). Ensuring the patients' family/carers are present and involved in education regarding physical activity is important. This is, however, a complex issue and carers of people with advanced lung cancer report established relationship boundaries often prevent them from promoting physical activity despite being aware of its importance (Rhudy et al., 2015). Notably, increased social support has been associated with reduced patient physical activity levels in advanced cancer (Ellis et al., 2017). The role of the carer ideally should be transformed to be a source of motivation for physical activity adherence (Ellis et al., 2012).

The strengths of this study include public recruitment, use of two independent transcribers and data coders, and reporting in line with established qualitative guidelines (Tong et al., 2007). Limitations include the small sample size which limits the generalisability of findings, and the relatively short duration of the focus group interviews which may impact on the quality of data. As participants were recruited from the general

community, we did not have access to their medical records and therefore cannot comment on their specific medical characteristics. The study may also be subject to sampling bias (towards participants favouring exercise) given the nature of recruitment. Further research is needed to understand the experience of people from non-English speaking backgrounds as well.

In conclusion, our study identified eight major themes with regards to the patient experiences of, and preferences for, physical activity after diagnosis. These were: the influence of past lifestyle and chronic disease; the perceived benefits of exercise after a lung cancer diagnosis; using exercise to facilitate return to activities of daily living; the impact of symptoms, capacity and motivation; family and peer support; access to services; health professionals; and enjoyment of different types of exercise. The patients suggested several factors that could have improved their healthcare experience. These include access to exercise professionals particularly after cancer treatment; access to information about physical activity in multiple different formats; supervision from health professionals and peer-support; and use of behaviour-change strategies to achieve sustainable increases in physical activity. Our results should be considered in the improvement of lung cancer care pathways as we strive to implement physical activity services into routine clinical care.

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Table 1: Major themes, sub-themes and additional supporting quotations

Major theme	Sub theme	Quotations from participants
Influence of past lifestyle and chronic disease	Lack of fitness	<i>“Ah that was a long time ago now, and I must say that I’ve not been a particularly physically active person subsequently”</i>
		<i>“I mean my breathing problems, I’ve always rather put down to being overweight and out of condition”</i>
	Sedentary behaviour	<i>“Unfortunately all my hobbies tend to be sedentary”</i>
	Self-blame	<i>“I thought well it’s my own fault, and no one else’s but then I noticed my breathing wasn’t right”</i>
Chronic diseases		<i>“I was constantly heading off to the doctor with chest infections and I also have arthritis”</i>
		<i>“I had to go to hospital, for a lady’s mechanical repair... and I went back to the GP for my cholesterol medication, you know, within a fortnight and he said how are you and I said I’m fine, he said you look fine, and I said I keep getting short of breath, and he sent me off for the x-ray.”</i>
Perceived benefits of physical activity	Experience of the positive benefits	<i>“I had cancer 10 years ago, and I went through, I had surgery and radiation and chemo, and 10 years ago...I’d just keep walking, um and I really felt that that contributed to how well I coped with the treatment 10 years ago. So from that experience I realised how important”</i>

“Well for the recovery process, and if you don’t do it well you are just going to go downhill”

“The only thing that might make that change, is if I saw, or convinced myself of the definite benefits”

“I found it helped my breathing...you need to be active to keep well. And I was feeling so horrible. Whatever I could do to try and build up my strength.”

Improved
mental health

“I used to walk... up and back, and during the day, because I couldn't, I was too restless, and I'd walk”

“I keep trying to do it and it was a way of distracting myself because I knew that I couldn’t get down to see anybody down here ... until January”

“There was a sort of mental aspect to it as well, I mean you were distracting yourself.”

Using physical
activity to
facilitate return
to ADLs

Keeping up
usual
activities

“To keep going as normal, try and ignore it”

“I think I’ve got to get out and do something, which I do...and I say well in case I run out of time so I’ve got to do it now, sort of thing”

“I think for me that’s part of the motivation and that frustration of not being able to do what I want to do physically, whether it was work, or work in the garden, I haven’t got back to yet, ... and getting back to my job which I really enjoy, so I think that was my motivation, yeah.”

Physical
activity as

“Management of within the household, to me that was something that was quite normal and that involves some activity, and so I could do that, so I could go and do some ironing for a while, and then go and have

part of ADLs to sit down and rest, or go and do the dishes, but just doing those it was sort of inbuilt exercises to go and sit down when I got really tired”

“The reason why I'm active is because if I don't do the things I do then no one else is going to do them, so I've got to get up and do them”

Walking for transport *“I would say I'm a physically active person, yes, I run the household, I do all the chores, um, I do all the shopping, and I don't drive a car, so I walk to the transport, like walk to the tram”*

Impact of symptoms, capacity and motivation

Influence of symptoms *“Some days I'd just get, I'd get too breathless and too tired, but yeah no I kept trying to do it and it was a way of distracting myself”*

“One can imagine all the fear would be beforehand, then you survive it and you get your result, and you know you're still alive so, but um even after that, for no, for no clear cognitive reason, you can't think of an actual practical reason, you can still get depressed, and I think it's dangerous for people if they don't know what's going on. And it will impact people's ability to do exercise, because you don't really care to any damn thing at all when you're depressed”

“My sleep patterns are pretty shot anyway... I guess some nights I just sit up until dawn”

“It's actually a hell of a trigger for depression, even if you feel kind of good, ok so the cancers been cut out and everything may be going quite well, you can still have a fall in the bit of a trough”

Worse during *“In my third week, when I hadn't had (chemo), that week I would go shopping and everything, the other*

- chemotherapy *two weeks I didn't because you know, I felt I was going to be sick any minute, sort of thing, so that's not really conducive to exercise, it didn't help, you know the shower itself was an effort"*
- Frustration *"I found that really frustrating, struggling even to just get up three stairs and I found that really frustrating."*
- "I was finding I was getting frustrated because I couldn't manage what I would normally do, so I would take off trying to do what I wanted to do, and just I couldn't do it. So to me, then doing those small steps became really important."*
- Exercise to improve symptoms *"Yeah and I always felt much better after my walk, and my walk in the morning, sort of planned my day, worked out what I was doing so I felt really good."*
- "Well for me I found it helped my breathing ... and you need to be active to keep well."*
- Weather *"Yeah sometimes I find I get really tired, and I find the cold air really affects me... so I sort of pick and choose when I go walking, because I find that really affects my breathing when I go walking"*
- Self-pacing, monitoring and progression *"I've found that to get my 10 thousand steps a day, even when I was doing the long walks, that's a lot of steps"*
- "I used to celebrate that I could walk from the front door to the front gate. That was a major thing, and then I started counting how many houses up the street? And each time I could go one more, I was really*

proud of myself”

Fear

“I do a walking group at the shopping centre 3 mornings a week, and I like that because it’s safe, secure and the ground is nice and even, and that’s as big or little as you’d like to make it”

“Finding out what your capabilities are and ahh reducing your fears about overdoing things, overexerting, reducing your partners fears about you know some sort of definite information about what is safe, what is not safe to do, what you should and shouldn’t do, would be I think, you know, for peace of mind, and family and friends piece of mind”

“I’m not brave enough to walk all the way to go do the shopping”

Family and peer support

Family and carers

“But I like to be out and doing, my husband just says rest”

“Actually, I’ve got resistance because my husband tries to stop me doing things, so I’ve got the washing in the machine, but he won’t let me hang it out.”

Peer support

“I would have been quite interested to talk to a couple of people that have been through the same thing”

“Well it says a quarter to 8 until a quarter to 9 because we’ve got to be out of the shopping center and I’ve got my, bag, you know, that t-shirt that says we belong to the group, it’s about 60 people”

“That notion that you’ve already made the contract to do something so you don’t...even if it looks a bit rainy or grizzly”

“Well I often wish that I did have someone to talk to about what I went through um you know, your family, although you love them, they’re not, not always interested, you know.”

“It’s ongoing with lots of people, so again, I get to talk to people there, and compare notes sort of thing.”

Access to services	Lack of time	<i>“I couldn’t always fit it in, well I enjoyed doing programs at the gym, but with my work I couldn’t always fit in, sometimes I would be really tired, didn’t like doing it at night, you know”</i>
	Follow-up care	<i>“So going in for a bit of surgery is that, although the service is fantastic and although you get extremely well looked after... if you’ve been whatever it is, the lung part, the lobe, the lungs been removed or, stent has been put in or whatever the thing is, and that’s the end of the story.”</i>
		<i>“It’s the follow up but it’s the medical follow up, it’s not to say, how has your life changed.”</i>
	Location	<i>“I’ve seen them (walking groups) in the um local paper, but they’re not I’m my area, they’re like maybe another suburb, you know and that ... me off because I’ve got to get from home to that suburb before I can do anything and that everything, which me off, I mean I would do it if one came up. No, because I don’t drive you see”</i>
	Cost	<i>“But to go back to gym now and have to pay, I just couldn’t afford it”</i>
		<i>“Mainly the cost at one stage, but there were times I went to the gym and it didn’t cost me anything which was good”</i>
		<i>“It [gym] would be if I had anything in mind. I mean I do just on the pension which is actually adequate,</i>

it's quite adequate but it doesn't provide for um anything, any luxuries."

Health professionals	Professional support	<i>"Yeah I go to this (walking group), and it's run by a personal trainer you know, so were supposedly doing all the right things."</i>
		<i>"I could extend or exert myself as much as possible, because I was in a very safe environment in the hospital, who had my hospital records."</i>
	Timing of support	<i>"I was telling other people what they told me and yet I was telling them misinformation so I was getting criss-crossed"</i>
		<i>"A lot of it was just forgot, went in one ear and out the other cause I couldn't retain it."</i>
	Methods of delivery of information	<i>"I can't use a computer, I'm hopeless with it"</i>
		<i>"I think a website is an adjunct, not as the only thing. I mean it would be useful but a lot of us are going to hate computers, and want to talk to a real person, and even have the chance to say oh look, somebody said I should drink water with this medication it will be better, is that true do you think? I mean somebody on the end of a phone"</i>
		<i>"I would much prefer to come and see somebody, but that's ah, rather than have them come and see me"</i>
		<i>"I think probably a combination because often when you are talking to a person you don't necessarily take it all in so therefore a pamphlet would be, or a website that you can really check in on to follow it"</i>

up.”

Group based
exercise

“Oh no I’m not into that [individual] personal trainer stuff, I’d rather go as a group”

“I’m sure you would have yards of literature to read, which I don’t think I’ve read at all, all about what was going to happen and how you would feel afterwards. But I just wanted, perhaps for me something like this maybe, a mothers group, you know they’ve all had babies, so they’ve got similar things, so perhaps like lung cancer group that meets once a month and you can go or not if you choose.”

Behavioural
change
strategies

“I probably would have like to have known, all I was told by the physio was try to keep walking as much as you can, and that was it, that was all I was told, I would have liked to have, someone to have, you know what about, well suggest that you incorporate this or this or this.”

“Every time I see my GP he tells me I have to walk more, and I agree with him because I think he’s correct, he knows what he’s talking about and it makes sense, but it hasn’t so far translated into...So it’s not a question of willpower, but it’s also not a question of getting good advice, I believe, the GP is absolutely correct, I should walk more, I have no quibble with that, I just haven’t worked out how to motivate myself, which appears at first sight to be a very sort of dull and inconvenient thing.”

“A bit more information and a bit more about what to do, what I can do, because I didn’t get any of that it was just like oh just walk and that’s what I’ve done”

“So if each person could find their key motivator it would be a lot, you know it would make a big, and I’m saying this because I was thinking to myself, yeah well, I haven’t got anything that is making me, you

know that I'm finding I can't do, because I've been sitting in front of a computer and I can sit and read a history book without being able to walk very far"

Enjoyment of
different types
of exercise

"I like walking"

"I have had no pleasure of jogging and ah walking fast for the sake of it, have held no interest for me at all."

"I don't really like to go to the gym or anything like that"

"It's very boring (treadmill), I'd much rather be out walking and looking at gardens or at the park"

"Lots of physical stuff you know, lifting heavy weights but I still loved it because I was getting active"

"Dancing, I'm a ballroom dancer, I still what's the word, kick all the boards. I'm quite good on my feet"

"Yep, probably an individual assessment, and then given some goals of what areas of your fitness or strength, um be good. Yeah to have that and then to join in and once you've got your program, to be part of a group"

"Weights, because I've done that and I quite enjoy it actually"

Abbreviations: ADLs, activities of daily living

Appendix 1: Semi-structured interview guide

- What does ‘physical activity’ mean to you?
- What amount of physical activity do you consider to be adequate for people with lung cancer?
- What do you believe are the benefits of physical activity for people with lung cancer?
- Do you believe that physical activity has a role in your treatment or recovery?
- What factors do you consider are most important in facilitating physical activity?
- What are the main factors that prevent you from being physically active?
- How do you prefer to undertake physical activity?
- Do you believe you have been provided with adequate information in regards to physical activity guidelines and benefits?
- How would you prefer to receive information in regards to access to and benefits of physical activity?



BARRIERS AND ENABLERS TO EXERCISE

FOLLOWING A LUNG CANCER DIAGNOSIS

PAST LIFESTYLE & CHRONIC DISEASE



History of sedentary behaviour & poor fitness
Self blame
Chronic diseases

EXPERIENCED BENEFITS OF EXERCISE

Improved physical and mental health



EXERCISE TO FACILITATE RETURN TO ACTIVITIES OF DAILY LIVING



SYMPTOMS, CAPACITY & MOTIVATION

Impact of symptoms & frustration
self-pacing, monitoring & progression



FAMILY & PEER SUPPORT



Family/carers misguided support promoting rest & avoiding exercise
Peer support to exercise

ACCESS TO SERVICES

Lack of time
Lack of exercise follow-up care
Location of programs
Cost



HEALTH PROFESSIONALS



Desire for professional support & group programs
Variety of information delivery methods
Behavioural change strategies
Timed to occur post-treatment

ENJOYMENT OF DIFFERENT EXERCISE

Diverse exercise preferences
Walking is popular
Pre-diagnosis exercise routine





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