The lived experiences, perceptions and considerations of patients with operable lung cancer concerning non-participation in a randomised clinical rehabilitation trial

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Introduction

Patients with lung cancer are difficult to recruit to and retain in research projects. A recent Danish randomised clinical trial experienced just this when recruiting patients with operable lung cancer to exercise rehabilitation after surgery. We were curious about why these patients did not wish to participate in the study despite the fact that participation in physical exercise by cancer patients has achieved good results in the past and is widely recommended by Danish health authorities.

Purpose

The purpose of this qualitative study was to explore perceptions and considerations of non-participation in a randomised clinical trial called Perioperative Rehabilitation in Operable Lung Cancer Patients (PROLUCA), and also the patients' lived experiences of their own life situation, health and need of support.

Methods

Reflective lifeworld research, which is a descriptive, interpretive phenomenological research approach developed by Dahlberg et al., was the underlying inspiration for this study. Fifteen non-participants consented to participate in qualitative interviews conducted 12-28 months (mean 21) after the patients had undergone a lung cancer operation but declined to participate in an exercise intervention.

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Findings

The patients' perceptions and thoughts concerning non-participation in rehabilitation are not just about the extent to which any change in health-related behaviour leads to better health. Many different factors play a role in how an individual person assesses the rehabilitation programme and how an individual person envisages a good or meaningful life. The essential meanings are presented as three themes:

Grey area between a healthy life and a good life

The patients narrated how it was meaningful to prioritise according to what was needed for them to live "a good life" after their illness. A good life for the patients consisted of activities that had inherent value, i.e. things they did for their own sake and which they chose to do, not just things they did to achieve something else. It can be difficult for patients to relate to exercise if their own values revolve around something else.

Under the influence of society – physical exercise as a norm

The patients described the importance of being physically active and they realised the benefits of exercising. The patients' descriptions of exercise however, came across as an embedded norm about exercise being something you ought to do. These patients experience themselves breaking with the values, expectations and guidelines for common behaviour that are rooted in society, namely that exercise leads to better health.

Health and exercise – a personal responsibility

The patients talked about how much responsibility they had for their own health, including physical exercise, and the analysis showed that many patients believe that they are personally responsible for exercising. It places the moral responsibility for activities related to own health with the individual patient and can lead to some patients feeling guilty if they fail to live up to this responsibility.

Conclusions

The patients' underlying narrative concerning values and the good life; priorities in daily life; social context and norms embedded in their self-understanding are crucial to gaining insight into when including patients in rehabilitation after lung cancer.