



**Thesis for the degree of Master of Public Health Sciences,
Centre of Public Health Sciences, Faculty of Medicine
School of Health Sciences,
University of Iceland**

**Quality of life among newly diagnosed lung cancer patients in
Iceland: The role of resilience and social support**

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May, 2018



HÁSKÓLI ÍSLANDS

Lífsgæði einstaklinga sem hafa nýlega greinst með lungnakrabbamein: Áhrif félagslegs stuðnings og seiglu

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Ágrip

Nýgreiningar og dánartíðni vegna lungnakrabbameins er enn hæst allra krabbameina í hinum vestræna heimi ef undanskilin eru nýgreiningar brjóstakrabbameina og blöðruhálskirtilskrabbameina. Að greinast með krabbamein hefur mikil áhrif á líðan sjúklinga en rannsóknir benda til verulegrar aukningar í tíðni ýmissa geðraskana á borð við kvíða og þunglyndis meðal nýgreindra krabbameinssjúklinga. Viðbrögð einstaklinga við greiningu krabbameins eru hins vegar mjög ólík, hugsanlega vegna mismunandi bjargráða og/eða seiglu einstaklinga sem og aðgengi að félagslegum stuðningi.

Markmið þessara rannsóknar var að kortleggja lífsgæði nýgreindra einstaklinga með lungnakrabbamein og meta áhrif félagslegs stuðnings og seiglu á alla meinþætti lífsgæða þeirra. Rannsóknarsniðið er framsýn ferilrannsókn. Þátttakendur voru 35 einstaklingar sem gengust undir greiningarrannsóknir vegna gruns um lungnakrabbamein. Þeir svöruðu spurningalistum um félagslegan stuðning og seiglu fyrir staðfesta greiningu og einnig spurningum um lífsgæði eftir að greining lungnakrabbameins var staðfest en áður en meðferð var hafin. Félagslegur stuðningur var metin með Berkman Syme Social Network Index (SNI) spurningalistanum og seigla var mæld með Connor Davidson seiglu skemanu (CD-RISC-10) fyrir greiningu lungnakrabbameins. Lífsgæði voru metin með spurningum úr Functional Assessment of Cancer Therapy-Lung (FACT-L). Meðalaldur þátttakenda var 71 ár og kynjahlutfallið var jafnt. Almennt tjáðu einstaklingar yngri en 70 ára meiri félagslegan stuðning miðað við þá sem voru eldri en 70 ára ($p=0,02$) en engin önnur tölfraðilega marktæk tengsl sást á milli bakgrunnspátta og félagslegs stuðnings og seiglu. Konur tjáðu meiri virkni (FWB) samkvæmt FACT-L lífsgæðakvarðanum samanborið við karla ($p=0,05$). Jákvæð tengsl voru á milli hærri félagslegs stuðnings fyrir greiningu og tengsla við vini og fjölskyldu (SWB) eftir greiningu ($p=0,02$). Engin tölfraðilegur munur sást á milli seiglu og lífsgæðapátta. Aftur á móti voru vísbendingar um að einstaklingar með meiri seiglu fyrir hefðu betri andlega (EWB) og almenna líðan (FACT-G) eftir greiningu, þegar leiðrétt hafði verið fyrir aldri og kyni ($p=0,09$). Þetta er fyrsta rannsóknin á Íslandi á lífsgæðum einstaklinga með nýgreint lungnakrabbamein. Þrátt fyrir fáa þátttakendur og takmarkað tölfraðilegt afl gefa niðurstöðurnar vísbendingar um að seigla og félagslegur stuðningur geti haft jákvæð áhrif á lífsgæði einstaklinga skömmu eftir greiningu lungnakrabbameins.

Abstract

Lung cancer is one of the most commonly diagnosed cancer world-wide and leading causes of cancer deaths in the developed world. A diagnosis of lung cancer is a severely stressful event illustrated by the dramatic increase in psychiatric disorders in newly diagnosed population. Nevertheless, there is a great variability in how patients respond to the diagnosis of cancer. This may be partly explained by the nature and quality of support that patients have, individuals coping skills and resilience.

The purpose of this study was to assess the quality of life of patients with newly diagnosed lung cancer and the potential role of social support and resilience on their quality of life. The study was a prospective cohort study at the pulmonary department at Landspítali, University Hospital in Iceland. The study cohort consisted of 35 patients referred for a diagnostic work up due to suspected lung cancer and followed until the lung cancer diagnosis was established. Social support was assessed with Berkman-Syme Social Network Index (SNI) and resilience was measured using Connor Davidson resilience scale (CD-RISC-10) at the diagnostic work up. Items from the Functional Assessment for Cancer Therapy-Lung Cancer (FACT-L) were used to measure quality of life after lung cancer diagnosis. The mean age of participants was 71 years; women representing half of the population. Younger patients (60-69 years) reported higher social support ($p=0.02$) compare to older patients (70 years or older), but no other statistically significant association was found between background/clinical characteristic and social support and resilience. Women reported better functional wellbeing (FWB) compared to men ($p=0.05$). Higher levels of social support prior to cancer diagnosis was associated with better social/family wellbeing (SWB) following cancer diagnosis ($p=0.02$). No statistically significant association was found between resilience and quality of life. Yet, both emotional well-being (EWB) and general well-being (FACT-G) were marginally associated with resilience ($p=0.09$) when adjusted for gender and age. This is the first study in Iceland on the quality of life of newly diagnosed patients with lung cancer. Although limited by small numbers the findings suggest that social support and resilience may be associated with better quality of life shortly after lung cancer diagnosis.

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List of Abbreviations

- CI= Confidence interval
- QOL= Quality of life
- FWB= Functional wellbeing
- EWB=Emotional wellbeing
- SWB=Social well being
- PWB= Physical well being
- LCS=Lung cancer subscale
- FACT-G= Functional Assessment of Cancer Therapy-Generic
- NSCLC= Non-Small Cell Lung Cancer
- SCLC= Small Cell Lung Cancer
- WHO= World Health Organization
- SD= Standard deviation

Introduction

1 Lung cancer

1.1 Incidence

Lung cancer is one of the most commonly diagnosed cancer worldwide and leading cause of cancer deaths in the developed world (World Health Organization, 2017).

In Iceland, it is the second most common cancer both in women and men, after breast cancer in women and prostate cancer in men (Icelandic Cancer Registry, 2015). In Iceland an average of 175 new cases were diagnosed annually, 82 in men and 93 women in 2011-2015 (Icelandic Cancer Registry, 2017). Lung cancer is responsible for 11% of all cancers diagnosed in Iceland (Icelandic Cancer Registry, 2015) and the five year survival rate is about 15% (Icelandic Cancer Registry, 2016). The incidence of lung cancer in men is similar in Iceland as in other western countries, but the incidence of lung cancer among women is one of the highest (Icelandic Cancer Registry, 2015). This has been partly explained by the relatively high smoking prevalence in Icelandic women in the fifties compared to women in other countries (Icelandic Cancer Registry, 2015). The Average age for diagnosis of lung cancer in Iceland is 70 years both women and men (Icelandic Cancer Registry, 2017).

1.2 Risk factors

Smoking is the primary cause of lung cancer and is estimated to be responsible for eight to nine out of every ten cases of lung cancer (Icelandic Cancer Registry, 2015).

Regardless of this strong association, only about 16% of smokers develop in the end lung cancer (Doll et al., 2004), indicating different susceptibility of the carcinogenic effect of the tobacco smoke (Guðbjartsson et al., 2008). The difference in susceptibility has been partly explained by hereditary factors (Jonsson et al., 2004; Schwartz et al., 2006). Regular smokers are not the only ones harmed by tobacco smoke, according to World Health Organization (WHO), around 600.000 individuals die every year due to second-hand smoking (World Health Organization, 2015). In Iceland, the smoking prevalence has declined significantly in the last decades, and according to data from 2014, there are only about 9-14% of all Icelanders who are daily smokers (Directorate of Health, 2015).

1.3 Diagnosis and staging of lung cancer

Lung cancer may remain asymptomatic and is therefore typically diagnosed at a late stage. Early diagnosis accounts for just 15-25% of lung cancer cases (Becker et al., 2012).

The benefits of an early diagnosis are clear. Patients diagnosed with non-small cell lung cancer at an early stage (stage IA) have five-year survival rate up to 70 % (Becker et al., 2012). Unfortunately, the majority or about 70 % of patients are diagnosed at a later stage of the disease (Guðbjartsson et al., 2008). At diagnosis up to 90% of patients have some symptoms of lung cancer;

cough, expectoration, blood-tinged sputum, respiratory distress and chest pain being the most common (Guðbjartsson et al., 2008).

1.3.1 Diagnostic procedures

When there is a suspicion of lung cancer, clinically or radiographically, number of procedures are performed to confirm the diagnosis and to assess the disease stage.

Following a chest X-ray, a computed tomography (CT) of the thorax is performed. The diagnosis is most often confirmed with a biopsy either through bronchoscopy or CT-guided biopsy of the tumor in the lung. Further analysis is performed to determine the disease stage, such as CT scans of the abdomen and brain, fluorodeoxyglucose positron emission, with or without contrast enhanced computerized tomography (FDG-PET +/-CT), as well as endobronchial ultrasound and mediastinoscopy (Guðbjartsson et al., 2008). In Iceland, most of the lung cancer diagnoses are performed at Landspítali University Hospital and up to half of all diagnoses are made through a fast diagnostic track assessment where structured analysis regarding diagnosis and staging of lung cancer is performed in a 1-2 days admission. A fast diagnostic track has documented positive effect on distress in patients and results in a faster decline in anxiety and depression following diagnosis of the lung cancer (Brocken et al., 2012; Hardardóttir et al., 2017).

1.3.2 Classification and staging of lung cancers

Primary carcinomas of the lung are traditionally classified as small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC) (Cancer Research UK, 2017).

NSCLC constitutes around 80-87% of all primary lung cancer with adenocarcinoma the most common, squamous cell cancer, large cell carcinoma and undifferentiated non-small cell lung cancer as the major histological types (Cancer Research UK, 2017). SCLC account for 13-20% of all primary lung carcinomas (Cancer Research UK, 2017). The main prognostic factor is the stage of the disease according to the histological type. Small cell lung cancer is then further divided into a limited disease and extensive disease (Simon et al., 2007). Small-cell lung cancer has a predisposition for early dissemination and patients are commonly diagnosed with a metastatic stage with metastasis commonly in the bones, liver, adrenals, brain, and the lungs (Elliot et al., 1987). Non-small cell lung cancer is staged according to the TNM staging (Vallieres et al., 2009). When using the TNM staging three factors are evaluated, the size of the tumor (T), spread to the lymph nodes (N) and other organs (M). According to the TNM descriptors the stage is determined, through stage 0-IV. The result of the staging is then used to plan treatment in addition to be the major prognostic factor of survival (Spira et al., 2004). Other factors like performance status, elevated LD in serum, inflammatory biomarkers (The modified Glasgow Prognostic score) and gender have shown to influence prognosis and survival (Guðbjartsson et al., 2008, Simmons et al., 2015, Spira et al., 2004)

1.4 Treatment and prognosis of lung cancer

Considerable progress has been made both in the diagnosis and staging as well as treatment of lung cancer over the years. The progress in treatments regimens have made the treatments more effective and less toxic thereby improving quality of life during treatment (Cancer care, 2018).

In spite of development in lung cancer treatments the prognosis of lung cancer is still poor, and the five-year survival rate is about 15% (Icelandic Cancer Registry, 2017). However, five years survival rate has increased from about 8% in the years 1960-1970 to 15% over the last decades (Guðbjartsson et al., 2008; Icelandic Cancer Registry, 2017). It is estimated that mortality due to lung carcinoma in the United States will exceed the death rate from breast, prostate, and colon cancer combined in the year 2017 (American Cancer Society, 2017). For patients with early stage non-small cell lung cancer (stage I and II) and for selected patients with locally advanced disease (stage IIIA), surgical resection is an optimal treatment (Guðbjartsson et al., 2008; Sasaki et al., 2014). Despite of advancements in treatment the risk of recurrence ranges from 30-75% (Sasaki et al., 2014) and the majority of recurrent tumors are distant occurring within the first 2 years after surgery (Sasaki et al., 2014). Treatment options for patients with lung cancer at advanced stage is usually either chemotherapy or radiation therapy or the combination of both, but the prognosis is poor (Guðbjartsson et al., 2008; Simmons et al., 2015; Spira et al., 2004). In the recent years there have been advances in molecular and genetic markers and corresponding targeted therapy giving hope for better results of treatment in cases of disseminated disease (American Cancer Society, 2017)

2 Distress and cancer

2.1 Distress and quality of life before diagnosis of cancer

An unexpected diagnosis of cancer and the need for treatment can cause negative impact on daily function and hence quality of life (Uchitomi et al., 2003). The prevalence of distress among cancer patients is high, and evidence shows that up to half of cancer patients experience emotional distress (Akechi et al., 2002; Zabora et al., 2001).

Emotional distress is a well-studied subject in cancer patients (Bultz et al., 2005; Linden et al., 2012; Steinberg et al., 2009). However, the impact of the diagnostic phase on emotional wellbeing has been overlooked. Researcher have focused mainly on distress during and after cancer treatment and less is known about anxiety and distress during the acute phase of diagnostic and treatment planning. Most studies about pre-diagnostic anxiety have focused on breast cancer patients which have shown from 30-60% of potential clinical anxiety (Brocken et al., 2012). Studies have shown that individuals confronted with the possibility of cancer diagnosis experience high level of anxiety in the diagnostic phase (Drageset et al., 2005; Ndukwe et al., 2012) which often is sustained after diagnosis (Brocken et al., 2012). Patient undergoing diagnostic procedures due to suspected lung cancer have shown to experience high levels of distress (Brocken et al., 2015) Furthermore patients in diagnostic phase, either for lung cancer or any other cancers, experience high level of distress and anxiety which affect quality of life and often results in prolonged anxiety and depression after diagnosis of cancer (Jensen et al., 2014). A systematic review of psychologic distress associated with the diagnostic phase of suspected breast cancer revealed that distress levels were heightened during the diagnostic phase (Montgomery et al., 2010) and women undergoing routine breast cancer screening experience high level of anxiety and distress (Gibbons et al., 2017). Even though individuals receive a benign diagnosis it can affect people's distress levels as shown in a qualitative study of 53 individuals diagnosed with a pulmonary nodule indicated that many experienced confusion and distress which sometimes lasted for months (Wiener et al., 2013). There is also evidence that the incidence of mental disorders starts to rise during the year preceding the diagnosis before any diagnostic procedures (Lu et al., 2016). In a meta-analysis by Chida and coworkers (Chida et al., 2008) on 165 studies assessing the association between mental distress measured before diagnosis of cancer and cancer risk, shows that psychological distress including depression, anxiety and poor quality of life were associated with the increased risk of cancer. There are several factors like medical history and education which influences individuals during the diagnostic period (Montgomery et al., 2010). A study on 21 patients with nonspecific symptoms which underwent a diagnostic evaluation for cancer revealed that quality of life in the diagnostic phase was related to the patients experience of symptoms, physical-emotional-and social functioning (Drageset et al., 2005; Moseholm et al., 2017). Furthermore, patients experienced high burden of anxiety and worry throughout the diagnostic

phase not only in the relation of the possible cancer diagnosis but also the impact that it might have on their family and friends (Moseholm et al., 2017).

3 Quality of life

3.1 Quality of life-definition

“Quality of life (QOL) refers to patient appraisal and satisfaction with their lives and functioning and is recognized as a subjective, multidimensional, and dynamic experience that reflects satisfaction with the control of disease symptoms and treatment side effects” (Liao et al., 2014).

Quality of life is primarily assessed by subjective measures, i.e. self-reported questionnaires (Moseholm et al., 2017). The concept of quality of life has many dimensions and generally refers to global QOL, symptoms, physical, psychological, social, role functioning and general health perceptions. (Liao et al., 2014; Wilson et al., 1995).

3.2 Cancer diagnosis and patient’s quality of life

A diagnosis of cancer indeed threatens the patient’s emotional health and many patients suffer from anxiety and depression (Linden et al., 2012).

Studies have shown that the prevalence of mental disorders like anxiety and depression among cancer patients ranges from 9.8%-38.2% (Mitchell et al., 2011; Singer et al., 2010). The result can be a variety of problems which can affect every aspect of one’s life. Physical issues like pain or functional impairment frequently affect the patient’s quality of life but also family related issues like uncertainty about individual’s role as well as existential concerns such as meaning of life and social isolation (Mehnert et al., 2012). A prospective study of psychological distress in lung cancer patients following curative resection indicated that distress at diagnosis to be predictive of distress at 12-month post-surgery (Uchitomi et al., 2003). In addition, studies have indicated that there is a relationship between number and severity of unresolved concern at diagnosis and later development of anxiety and depression in lung cancer patients (Hill et al., 2003). There is a growing consensus that cancer treatment should be judged not only on the effect on quantity but also quality of life (Suthahar et al., 2008). Quality of life is for example assessed in all clinical trials and provides a useful information to both patients and clinicians. None the less quality of life is infrequently evaluated in a daily clinical practice (Suthahar et al., 2008).

3.2.1 The impact of quality of life on survival

Quality of life is not only a question about psychosocial issues or reduced distress. Number of studies have shown that lower quality of life is associated with shorter survival among cancer patients (Movsas et al., 2009; Temel et al., 2010). A study of 48 newly diagnosed lung cancer patients conducted in Canada indicated that baseline quality of life assessment (measured with the functional assessment of cancer therapy-general form, FACT-G) was significantly associated with lung cancer specific survival (Dharma-Wardene et al., 2004). The overall findings, after adjusting for cancer stage, confirmed that individuals who reported lower quality of life at diagnosis had shorter survival compared to those who reported a higher quality of life (Dharma-Wardene et al., 2004). Other studies have further reported various psychiatric morbidities to be associated with increased risk of lung cancer specific mortality (Zhu, et al., 2017, Sephton et al., 2013).

3.3 Quality of life among lung cancer patients

Cancer patients often experience multiple symptoms related to treatment. A systematic review conducted by Esther Kim and colleagues (Esther Kim et al., 2009) where the prevalence and impact of multiple symptoms in cancer patients receiving active treatment was examined. Their results indicate that cancer patients experience multiple symptoms and about 40% of patients experience more than one symptom, where fatigue and worry/anxiety are the most predominantly symptoms (Esther Kim et al., 2009).

Previous studies suggest that lung cancer patients receiving therapy, either chemo, surgical or radiation therapy, experience multiple co-occurring symptoms, which have a negative impact on their functional status and quality of life (Akin et al., 2010; Raz et al., 2016; Reilly et al., 2013). When compared to all other cancer patients, lung cancer patients usually report the lowest quality of life (Akin et al., 2010). A study of over 45,000 Canadian patients with various cancers showed that lung cancer patients reported the highest level of disease-related symptoms (Barbera et al., 2010). In addition, lung cancer patients experience the most intense disease related symptoms of all cancer patients (Akin et al., 2010). This is partly because of poor prognosis and severe treatment-related side-effects during the disease trajectory (Sprangers et al., 2002). Furthermore, lung cancer patients often feel stigmatized by their disease which may also significantly compromise their emotional quality of life (Chambers et al., 2015). In lung cancer, health related stigma results from the strong association between smoking and risk of lung cancer, enhancing the public perception that the disease is self-inflicted (Chambers, Dunn, et al., 2012). Nevertheless; there is a great variability in how patients respond to the diagnosis of cancer. This may be partly explained by the nature and quality of social support that patients have access to (Eom et al., 2013) or, individual coping skill or resilience (Brennan, 2001). Evidence suggest that psychosocial characteristics may either work as a moderating or mediating factor regarding symptoms experienced and patient's outcome (Daly et al., 2007).

3.4 Interventions to enhance quality of life

Physical and psychological distress is relatively common among newly diagnosed lung cancer patients which in some cases causes clinically confirmed depression and anxiety disorders (Steinberg et al., 2009). Furthermore, there are evidence suggesting that newly diagnosed lung cancer patients experience more psychosocial distress than physical distress (Liao et al., 2014). Factors like uncertainty, worry and fear of death can cause distress among lung cancer patients (Lehto, 2011).

To be able to provide effective psychosocial care it is important to understand the types and correlates of supportive needs in people diagnosed with lung cancer. In a study of inoperable lung cancer patients indicated that 27% of participants identified that contact with the health care system as causing the most concern during the first-year post-diagnosis (Tishelman et al., 2010). Other studies have indicated that cancer patients strongest perceived needs is for the health care providers to take time to listen, discuss and support (McIlmurray et al., 2001). Palliative care is well established

among lung cancer patients with stage IV disease. There is growing evidence that palliative care is necessary in earlier disease stages whereas patients experience multiple symptoms, either disease related or treatment related symptoms, and increased psychosocial needs associated with the uncertainty of possible recurrence (Koczywas et al., 2013). Early nursing intervention have shown to minimize distress and improve quality of life, both in the curative and palliative setting (Temel et al., 2010). A study by Temel and colleagues where patients with newly diagnosed metastatic non-small cell lung cancer were randomly assigned to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life was assessed by nurses at baseline and at 12 weeks using FACT-L (The functional assessment of cancer therapy-lung). The patients receiving the intervention reported better quality of life and had better survival (Temel et al., 2010). Another study analysing quality of life among patients with non-small cell lung carcinoma who underwent a surgical resection, found that patients randomly assigned to interdisciplinary intervention such as quality of life assessment and education sessions conducted by nurses had enhanced quality of life at 12 months' post-surgery compared to standard care (Raz et al., 2016). Simple intervention like telephone calls have shown to have a beneficial effect on quality of life. Study of 60 newly diagnosed lung cancer patients receiving their first chemotherapy indicated that those patients followed with a telephone call demonstrated significantly less adverse events due chemotherapy and higher social functioning quality of life scores (Hintistan et al., 2017). Finally, a study of 109 people newly diagnosed with lung cancer in California, demonstrated high levels of distress and unmet supportive care (Sanders et al., 2010). The patients expressed interest in treatment that could improve distress and other factors influencing quality of life. Those findings emphasise the importance of assessment of distress and quality of life in patients undergoing treatment for lung cancer (Sanders et al., 2010).

4 Resilience

4.1 What is resilience?

Generally, resilience refers to one's ability to "cope well" with adversity and one's ability to preserve or recover mental health despite experiencing difficulty (Charney, 2004; Connor et al., 2003).

Resilience has often been defined by baseline characteristics or traits, which enable individuals to thrive in the face of adversity (Connor, 2006; Richardson, 2002). Examples of these characteristics or traits are basic demographic variables and personal resources, such as hope, motivation, optimism, pre-existing social support, and spirituality (Molina et al., 2014). Others have defined resilience as a mechanism of positive adaptation, like coping strategies, that changes over time and protects against psychological distress. (Mancini et al., 2009). In nursing science, resilience has been defined as a resistance or recovery of mental health after challenge (Szanton et al., 2010). Although both coping and resilience focus on response to stress the concepts are distinct in that way that coping involves a set of skills, whereas resilience indicates a successful result of the exercise of those skills (Compas et al., 2001; Mancini et al., 2009) Even though everyone uses some kind of coping skills they are not necessarily resilient. Thus, according to this view, when coping skills result in a good outcome that person is resilient (Compas et al., 2001). An example of a successful coping skills is seeking information about the diagnosis and treatment of cancer. Studies have shown that those cancer patients who actively seek information about their treatment plan reported reduced anxiety compared to those who did not (Bronner et al., 2017). Resilience can be promoted with interventions such as teaching active stress management, coping skills, mindfulness, and goal setting which can influence this mechanism and act as a buffer for distress (Molina et al., 2014). Factors that contribute to persons resilience can be personal factors, like optimism, and environmental factors most notably social support (Matzka et al., 2016).

4.1.1 Resilience across age groups and gender

Studies generally report lower emotional distress in older patients with cancer compared to younger patients with cancer (Graves et al., 2007; Hinz et al., 2009; Kornblith et al., 2007).

A study of 92 individuals, aged 27-87 years, diagnosed with colorectal cancer indicated that older age and male were associated with higher resilience and lower distress (Cohen et al., 2014b) in addition resilience was found to be a mediator between gender and emotional distress (Cohen et al., 2014b).

4.2 The role of resilience in coping with cancer

Studies have reported high resilience to be associated with less anxiety in samples of cancer survivors (Scali et al., 2012) as well as in cancer patients undergoing treatment (Min et al., 2013). Several studies on cancer patients and resilience have reported an association between resilience and lower of emotional distress and higher quality of life (Lafaye et al., 2014; Min et al., 2013; Popa-

Velea et al., 2017). In addition, it has been indicated that individuals who are resilient use more effectively social support (Costa et al., 2017)

Among newly diagnosed cancer patients, patients with greater internal strength, as a mark of resilience, at the time of diagnosis reported reduced distress, better coping strategies, and improved quality of life (Jim et al., 2006). Long time survivors of breast, stomach, and lung cancer who had exceeded their life expectancy, showed that resilience was associated with better quality of life and lower levels of depression (Gotay et al., 2004). The findings from a recent Icelandic study suggests that resilience measured in 44 patients before the diagnosis of prostate cancer may influence distress later on (Ragnarsdóttir, 2012). The overall results of that study indicated that those patients who reported higher resilience at diagnosis experienced less distress three month after diagnosis (Ragnarsdóttir, 2012). Need for supportive care has been associated with resilience. A study of cancer patients, where the vast majority had undergone either surgery and/or chemotherapy, and were starting radiation therapy indicated that those patients expressing higher resilience at baseline had less need for psychosocial support (Brix et al., 2008). Resilience and social support were reported as critical factors in enhancing quality of life in a cross-sectional study of Chinese bladder cancer patients (Li et al., 2016). The results indicated that patients who demonstrated high resilience had more fighting spirit and adjusted better to psychological difficulties (Li et al., 2016). Finally, Liao and colleagues found that self-efficacy, or the people's belief in their capabilities of coping with cancer and its symptoms, significantly influenced the quality of life in newly diagnosed lung cancer patients (Liao et al., 2014).

5 Social support

5.1 Social support: definition

Social support is defined as a network of family and friends who provide emotional and practical assistance which has been shown to help cancer patients to maintain health and independence (Jatoi et al., 2009; Luszczynska et al., 2013; Sjolander et al., 2008).

Social support has been divided into perceived and received social support. Perceived social support refers to perception concerning availability of support (Luszczynska et al., 2005). It is the individuals discernment that leads them to believe that they are cared for and valued and that they belong to a network of communication and mutual obligation, while received support refers to the actual supportive behaviour (Banik et al., 2016; Luszczynska et al., 2005, Sammarco, 2009). Evidence have shown that perceived social support may be more critical than received social support in term of quality of life outcomes (Schroevers et al., 2010; Wethington et al., 1986)

5.2 The effect of social support on quality of life and distress

Several factors have been found to be associated with anxiety and depression at the time of cancer diagnosis, including sociodemographic factor and social support (Costa et al., 2017).

Social support may be an important factor how well patients adapt to the cancer diagnosis and treatment. Social support has been shown to mitigate the adverse psychological effects of cancer diagnosis by acting as a coping resource and lower distress after cancer diagnosis and shown to be beneficial regarding adjustment to a cancer diagnosis (Banik et al., 2017, Ellis et al., 2013 , Luszczynska et al., 2013, Parker et al., 2003). In a study on patients with breast and prostate cancer indicated that those who experienced higher levels of social support reported lower levels of distress at the time of diagnosis (Baider et al., 2003). In addition higher perceived social support pre-treatment has shown to lower the risk of depression post treatment of cancer as shown in a study of patients undergoing bone marrow transplant (Jenks Kettmann et al., 2008). There is evidence that suggests that social support directly affects health, both mental and physical, of cancer patients and a lack of social relationship may results in higher risk of cancer related mortality (House et al., 1988; Wells et al., 2009). Studies on cancer patients have shown that social support is associated with fewer psychological symptoms and greater wellbeing (Bowers, 2008), it also has shown to be a protective factor against negative health outcomes including mortality (Schroevers et al., 2010). Indeed, several studies have revealed an association between various indicators of social support and cancer-related mortality (Pinquart et al., 2010) and improved health-related quality of life (Falagas et al., 2007; Jatoi et al., 2009; Luszczynska et al., 2013; Weihs et al., 2005). Received social support has also shown to be important regarding quality of life. Individuals with strong social network tend to seek medical help earlier when having symptoms of disease, and are therefore diagnosed with cancer at an earlier stage compared to individuals with constrained social network (Pedersen et al., 2011). In a meta-analysis by Adams and colleagues on social constrain and distress in cancer patients revealed that relationship between social constrain and distress was higher among those who were newly diagnosed with cancer (Adams et al., 2015). The size of the social network can also be perceived as unsupportive by the patients if displayed as uninvited advice or avoidance (Herzer et al., 2006).

5.3 Gender difference in social support

The benefit of social support may further be gender related. A study of 342 cancer patients where the relationship between perceived social support, size of the social network and depression was evaluated indicated that higher perceived social support was associated with less depression in patients (Hann et al., 2002). With an increased number of relatives and friends there was a significant association with less depression in women while no association between these factors was found in males (Hann et al., 2002).

When faced with a major stressor like cancer diagnosis evidence shows that women are more likely to seek out professional help and support compared to men (Clarke et al., 2006). Also there are data that suggest that women with a larger network of support were more likely to rely on family and friends for support while, whereas men were more likely to rely exclusively on their partner (Antonucci et al., 1987) Women are also more likely than men to express emotion and communicate symptoms (Boudioni et al., 1999; Clarke et al., 2006). In a systematic review by Fish and colleagues on psychosocial factors that influence men's help seeking for cancer symptoms indicated that support of spouses and family members was the strongest facilitating factor associated with men's help seeking behaviour (Fish et al., 2015).

5.4 Social support across age groups and the effect on quality of life

Differences in social support has also been observed between individuals of different ages and evidence show that advanced age to be a predictor of a poorer social support network (Hann et al., 2002).

Study of breast cancer survivors revealed that older breast cancer survivors often experienced shrinking network of support over time with the occurrence of divorce, widowhood and deaths of friends and family (Bloom et al, 2004). In a study of age difference in decision making regarding cancer treatment, indicated that older patients reported less received social support and were less influenced from their social network on their cancer treatment compared to younger patients (Krok-Schoen et al., 2017). A study of social support and hope in relation to age in women with advanced breast cancer and their spouses, showed that depression was lower among older women and their spouses compared to younger couples. In addition, younger women seemed to rely more directly on social support to cope with depression while older women hope was found to mediate the relationship between social support and depression (Hasson-Ohayon et al, 2014). Finally, a study of Chinese cancer survivors of different cancer where the relationship between social support and adjustment to cancer in relation to age and gender, indicated that support from society had a stronger positive association with quality of life and a support from friends had a stronger negative association with quality of life among younger survivors compared to older survivors (You et al, 2014).

In the general population older age is often associated with lower quality of life while this opposite in cancer populations (Holzner et al., 2004; Michelson et al., 2000). A study of cancer patients with bone metastasis revealed that older patients reported better quality of life compared to younger patients (Wong et al., 2013). Studies on breast cancer patients consistently show greater depression

and lower quality of life among younger women compared to older women (Avis et al., 2013; Howard-Anderson et al., 2012). Younger age may be associated with lower quality of life among cancer patients because of the traumatization of being diagnosed with a life-threatening disease at a young age. Furthermore, younger patients still have greater family and community responsibility than older patients which may cause additional deterioration in quality of life (Wong et al., 2013; Zimmermann et al., 2011)

5.5 Social support and marital status

Finally, marital status as an indicator of social support has been shown to influence quality of life (Badr et al., 2006) and survival (Carmack Taylor et al., 2008) among cancer patients.

A study based on the Norwegian cancer registry of almost 20.000 lung cancer patients indicates that never married individuals diagnosed with cancer had between 47 to 56% higher risk of mortality compared to married individuals, the relative risk was higher among men compared with women, after adjustment for cancer site, stage, time since diagnosis and education (Kravdal, 2013). The strong relationship between marital status and cancer survival was confirmed in a meta-analysis by Pinguart and colleagues of 87 studies (Pinguart et al., 2010). The overall results suggest that unmarried patients had, compared to married patients, relatively higher risk of cancer-specific mortality (Pinguart et al., 2010) .

6 Study rationale and aims

The diagnosis and treatment of cancer may be associated with increased anxiety levels and lower quality of life among patients. However, the magnitude of the influence of a cancer diagnosis on quality of life varies greatly across patient populations as well as across different studies (Esther Kim et al., 2009; Linden et al., 2012). Certain demographic characteristics have been found to be related to how well individuals adjust to cancer. Gender and age have shown to be influential regarding psychological distress following cancer diagnosis (Avis et al., 2013; Linden et al., 2012). Furthermore, married individuals report less distress and better adjustment compared to unmarried individuals (Broeckel et al., 2000).

Little is known about the quality of life of Icelandic patients with newly diagnosed lung cancer. As stated above there is evidence to suggest that higher levels of perceived social support and resilience may protect cancer patients from distress and compromised quality of life after the lung cancer diagnosis (Carmack Taylor et al., 2008; Mancini et al., 2009). Even though many studies have studied quality of life among cancer patients, few studies have assessed the impact of social support and resilience on quality of life among newly diagnosed lung cancer patients. Two Icelandic studies have evaluated resilience and social support on distress and quality of life. The first one evaluated the influence of resilience and social support on distress in patients with newly diagnosed prostate cancer indicating that resilience was a mediating factor on distress while social support did not show any effect on quality of life (Ragnarsdóttir, 2012). The latter study evaluated the association between distress and social support in Icelandic women during breast cancer diagnostic phase. That study indicated that social support was identified as a fundamental coping resource, where emotional support from spouse and family was of utmost importance (Fridfinnsdottir, 1997).

With this background, we will in the present study explore quality of life among patients with newly diagnosed lung cancer and the potential association between perceived social support and resilience and different aspects of quality of life among these patients right after diagnosis.

Article

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Quality of life among newly diagnosed lung cancer patients: The role of social support and resilience

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Abstract

Purpose/Objective: To assess the quality of life of patients with newly diagnosed lung cancer and the potential role of social support and resilience on their quality of life. **Methods:** The design was a prospective cohort study conducted in a pulmonary oncology unit at the University Hospital of Iceland. Patients (n=35) were recruited when referred for a diagnostic work up due to suspected lung cancer and followed until after lung cancer diagnosis. Items from Functional assessment of cancer therapy-Lung Cancer (FACT-L) were used to measure quality of life after lung cancer diagnosis. Social support was assessed with Berkman-Syme Social Network Index (SNI) and resilience was measured using Connor Davidson resilience scale (CD-RISC-10) at the diagnostic work up. **Results:** Mean age of participants was 71 years; women representing 48.6 %. Younger patients (60-69 years) reported higher social support ($p=0.02$) compared to older patients (70 years or older) but no other statistically significant associations were found between background/clinical characteristics and social support and resilience. Women reported better functional wellbeing (FWB) compared to men ($p=0.05$). Higher levels of social support prior to cancer diagnosis was associated with higher social/family wellbeing (SWB) following cancer diagnosis after adjusting for age and gender ($p=0.01$). Resilience was marginally associated with emotionally well-being (EWB) and generic quality of life (FACT-G) ($p=0.09$), although the association was not statistically significant. **Conclusion:** This is the first study in Iceland on the quality of life of newly diagnosed patients with lung cancer. Although limited by small numbers the findings suggest that social support and resilience may be associated with better quality of life shortly after lung cancer diagnosis. **Implication for Nursing:** Patients diagnosed with lung cancer represent a vulnerable group in need of extensive nursing support. Knowledge about factors influencing quality of life may inform interventions to improve QOL in lung cancer patients

Lung cancer is one of the most common cancer world-wide and leading cause of cancer deaths in the developed world (World Health Organization, 2017). In Iceland an average of 175 new cases were diagnosed annually in 2011-2015 (Icelandic Cancer Registry, 2017). Prognosis in lung cancer is poor, five-year survival is about 15% and has not changed much over the last decades (Icelandic Cancer Registry, 2017). At diagnosis the majority of the patients are symptomatic and about 70% of all cancer cases are diagnosed at an advanced stage (Guðbjartsson et al., 2008). A diagnosis of cancer threatens the patient's emotional health and many patients suffer from anxiety and depression (Linden et al., 2012). Nevertheless, there is a great variability in how patients respond to the diagnosis which may partly be explained by the nature and quality of support that patients have as well as individual coping skills or resilience (Brennan, 2001).

Quality of life

Emotional distress is a well-studied subject in cancer patient (Bultz et al., 2005; Linden et al., 2012; Steinberg et al., 2009). However, the impact of the diagnostic phase on emotional well-being has often been overlooked. Individuals with suspected lung cancer experience high distress levels which often remains after the diagnosis (Brocken et al., 2015).

Quality of life assessments in cancer care are getting more common with the increasing understanding of psychobiological factors and how psychosocial characteristics can either work as a moderating or mediating factor to symptoms experienced and patient outcomes (Daly et al., 2007). Higher quality of life has been linked to better survival. Results of a study on 42 patients with advanced lung cancer undergoing their first chemotherapy indicated that higher baseline quality of life scores were significantly associated with improved survival of patients with lung cancer (Dharma-Wardene et al., 2004). Patients with lung cancer have been reported to experience the worst quality of life as compared to other cancer patients (Liao et al., 2014) and experience the highest intensity of physical symptoms, both due to the disease and treatment (Akin et al., 2010). These symptoms may influence their quality of life with secondary effect on including emotional-, social-, and physical dimension of their quality of life (Akin et al., 2010). Nevertheless, there is a great variability in how patients respond to the cancer diagnosis.

Resilience

Resilience refers to one's ability to cope well when faced with a distressing situation (Connor et al., 2003) or a baseline traits which enables individuals to thrive in the face of adversity (Connor, 2006; Richardson, 2002).

Studies have shown that both newly diagnosed cancer patients and survivors with high degree of resilience adjust better after diagnosis of cancer and have higher levels of quality of life (Chambers, Meng, et al., 2012; Li et al., 2016). Little is known about the role of resilience in the quality of life of newly diagnosed lung cancer. Yet, a study of resilience among survivors of lung, breast and stomach cancer showed that resilience was associated with improved quality of life and lower level of depression (Gotay et al., 2004).

Social support

Social support has been shown to mitigate the association between cancer diagnosis and anxiety and depression at the time of cancer diagnosis (Costa et al., 2017).

Social support is defined as a network of family and friends who provide emotional and practical assistance to maintain health and independence (Jatoi et al., 2009; Sjolander et al., 2008). There is evidence suggesting that social support directly affects health and lack of it may result in higher risk of mortality of any cause (House et al., 1988; Wells et al., 2009). A study of newly diagnosed cancer patients revealed that patients who reported higher levels of social support had lower levels of psychological distress compared to those who reported a lower level of social support (Baider et al., 2003). A cross sectional study of Chinese patients with bladder cancer revealed that resilience and social support was a critical factor to enhance quality of life (Matsuda et al., 2003). Meanwhile, little is known about social support in lung cancer patients and how the degree of social support affects quality of life of newly diagnosed patients with lung cancer.

Specific aims

In this prospective cohort study on patients with newly diagnosed lung cancer, the primary aim was to describe the quality of life of newly diagnosed lung cancer patients and to explore the association between perceived social support or resilience and various aspects of quality of life in this patient group. This is the first prospective study in Iceland on quality of life of patients that specifically have recently received the life-threatening diagnosis of lung cancer.

The study hypothesis was as followed:

Patients with newly diagnosed lung cancer with high levels of perceived social support and resilience at baseline report better quality of life after diagnosis, compared with patients with low levels of perceived social support and resilience.

Methods

Procedures

All data was retained from an ongoing prospective cohort study (the LUCASS study) at the pulmonary department at Landspítali, University Hospital in Iceland.

Patients with clinical or radiographic changes suggestive of lung cancer and referred to our hospital go through a diagnostic work-up, leading to a definite lung cancer diagnosis and staging during a 24-hour diagnostic course or within few days thereafter (Hardardottir et al., 2017). Eligible for the study were all individuals with suspected lung cancer undergoing the diagnostic procedure at our hospital, 18 years and older and younger than 86 years and who were able to answer questionnaires in Icelandic on their own or with help of family member or a study nurse. After signing an informed consent, participants answered questionnaires during the diagnostic work up due to suspected lung cancer (assessment 1), and again after the lung cancer diagnosis was confirmed but

before starting treatment start (assessment 2) (Figure 1). Number of individuals participated in the study and answered questioners in assessment 1 were 87. Of those, 67 were diagnosed with lung cancer and were eligible for the second questionnaire (assessment 2). Of those 67 patients diagnosed with lung cancer 35 patients finalized questionnaire at assessment 2 as seen in figure 2. The reason for dropout in assessment 2 are variable as seen in figure 2.

Measures

Apart from standard sociodemographic questions, the measures from the LUCASS questionnaire were used for the purpose of the current study: Social support (Berkman Syme Social Network Index (SNI), resilience (The abridged CD-RISC-10) in assessment 1 and quality of life measured with items from the Functional Assessment of Cancer Therapy-Lung Cancer (FACT-L) in assessment 2.

Quality of life was measured with items from FACT-L (Functional Assessment of Cancer Therapy-Lung Cancer). FACT-L entails items from The Functional Assessment of Cancer Therapy-general form (FACT-G), developed in the early 1990s, comprising of 27 questions, which together address four dimensions: Physical well-being (PWB), social/family well-being (SWB), emotional well-being (EWB), and functional well-being (FWB). In addition, it includes lung cancer specific questions on for example shortness of breath and coughing, weight loss and loss of appetite and smoking history.

FACT-L has been shown to be a reliable and valid measure of quality of life, with the internal consistency varying between .053 to .68 and a coefficient α 0.89 (Cella et al., 1995). All items are scored on a 5-point Likert scale (0=not at all; 4=very much). Higher scores indicate better QOL, and the total score ranges from 0 to 144 (Cella et al., 1995). FACT-L has not our knowledge been used in Icelandic studies before. For the purpose of the current study, items from the FACT-L were translated to Icelandic by Unnur Valdimarsdóttir and Heiðdís Valdimarsdóttir with back-translation to English to ensure their homogeneity with the original version. Three questions were dropped from the original version as they were judged as not relevant for the newly diagnosed lung cancer population responding to our questionnaire before treatment start. The following questions were dropped: "I am bothered with side effect of treatment", "I am satisfied with my sex life" and "I regret my smoking." Because of the three questions dropped in the current study, the total score ranges from 0-132 instead of 0-144 in the original version (Cella et al., 1995).

The Berkman-Syme Social Network Index (SNI) is a self-reported questionnaire providing a composite measure of social support and connections.

SNI includes four types of social connection: Marital status, sociability, close relatives, and close friends (Kroenke et al., 2006). It allows researchers to categorize individuals into four levels of social connection, from social isolation, moderately isolated, moderately integrated and finally to highest level of social integration which is socially integrated (Berkman et al., 1979; Kroenke et al., 2006) and has been widely used in both clinical practice and research settings (PhenX Toolkit, 2017).

SNI was translated into Icelandic, with back-translation into English, and tested for the first time in the SAGA cohort study of 921 participants (University of Iceland, 2014).

Connor-Davidson Resilience Scale (CD-RISC-10) is a ten-item scale which measures patients' capability to cope with adversity. It measures a subject's self-evaluation of prior experience in successfully overcoming stressful events and positive changes (Scali et al., 2012).

The CD-RISC reflects the ability to bounce back from the variety of challenges that can arise in life (Campbell-Sills et al., 2007). The original CD-RISC is a 25-item scale assessing resilience during the last month, with higher scores reflecting higher resilience capacity. Each item is rated on a 5-point range and the total scores range is from 0-100 (Connor et al., 2003). The abridged CD-RISC-10 version reflects the ability to tolerate experiences such as change, personal problems, illness, stress and failure (Scali et al., 2012). The CD-RISC-10 has been found to display good internal consistency, convergent and discriminant validity, and construct validity (Campbell-Sills et al., 2007). A study of resilience among adult women showed high internal consistency (Cronbach's $\alpha=0.88$) (Scali et al., 2012). The CD-RISC-10 was translated into Icelandic by Sjöfn Ágústsdóttir and translated back into English by Jakob Smári and the internal consistency in the Icelandic translation was $\alpha=.79$ (Ragnarsdóttir, 2012).

Tumor stage and type

Lung cancer staging was according to the 7. edition of TNM staging for both non-small and small cell lung cancer. The TNM (tumor, node, metastasis) staging are commonly used in staging the non-small cell lung cancer (NSCLC) but can be applicable in small cell lung cancer (SCLC) (Vallieres et al., 2009).

Data Analysis

All data analysis was conducted using R-studio version 1.0.136 (R Core Team, 2014). Descriptive statistics of demographic and main studied variables were indicated with the mean (\bar{X}) and standard deviation (SD) or as number (N) and percentage (%), as appropriate. Background characteristics of individuals with low versus high social support as well as low versus high resilience at assessment 1 (before diagnosis) were presented. A median split was done to categorize resilience into low vs. high. The total social support score was constructed according to the previously published methodology (Kroenke et al., 2006; Sapp et al., 2003). The following factors were assessed when social support scoring was determined: marital status, one point for yes and zero for no. How many close friends and relatives, 0-2 =0 point and all other scores =1 point. Participation in group, no=0 point and yes =1 point and finally participation in religious meetings, less than or equal to every few months =0 point all other scores =1 point (Loucks et al., 2006). If the total score of each participant was 0 it indicated low social support, scores from 1-2 indicated median social support and scores from 3-4 indicated high social support. Due to the small sample size in the current study participants who were categorized as low and median were merged in to one group of low/medium social support which resulted in two groups; low/median social support and high social support

Fisher's exact test was used to examine the difference in baseline characteristic between low vs high social support and low vs high resilience. The outcome variable, quality of life, was presented across variation in social support and resilience using linear regression. The association between predictors, social support, and resilience at assessment 1, and the outcome, quality of life at assessment 2, was tested using linear regression accounting for potential covariates. All models were stratified or adjusted for gender and age. Some values on resilience were missing allowing for imputation of 5 datasets using Mice package in R-studio.

Results

Patient Characteristics

Background information and demographic characteristics are presented in table 1. The mean age of the 35 participants was 71 years (61-83 years, SD \pm 6.1) with equal gender distribution. Most of the participants had spouses or 22 (62.9%) and majority of the participants had primary education (57.1%). At diagnosis 54.3% of the patients were diagnosed with lung cancer at stage I-II and 45.7% at stage III-IV. Of the 35 patients only two had small cell lung cancer (SCLC) and the remaining patients had non-small cell lung cancer (NSCLC).

Social support and resilience

Table 2 shows degree of social support and resilience in our study population according to background and clinical characteristics. Patients younger than 70 years old tended to report higher degree of social support compared to individuals older than 70 years old ($p=0.02$). No other statistically significant association was found between background/clinical characteristic and social support or resilience in our study population.

Quality of life

Quality of life was similar across background and clinical characteristics (table 3) with few exceptions. Functional wellbeing (FWB) was significantly higher among women compared to men (mean 21.4 and 18.0 respectively, $p=0.05$). Patients older than 70 years tended to score lower on symptoms specific for lung cancer (LCS) than younger ones (mean 12.8 and 15.0 respectively, $p=0.02$). Finally, the LCS score was higher, indicating lower lung cancer symptom's, among individuals diagnosed with lung cancer less disseminated, stage I-II compared to those diagnosed at stage III-IV (mean 14.8 and 13 respectively, $p=0.05$)

Table 4 shows the association between social support and resilience with several quality of life domains. Social support seemed only robustly associated with social wellbeing (SWB) ($p=0.02$), adjusting for age and gender affected the association minimally, ($p=0.01$). Social support was not associated with other quality of life domains. Resilience was not statistically associated with any of the quality of life domains. Yet, resilience was marginally associated with general well-being (FACT-G) score ($p=0.09$) and emotional wellbeing (EWB) score ($p=0.09$), when age and gender were added

to the model. Other quality of life domains were not statistically significantly associated with resilience.

Discussion

The key findings of the current study are that women with newly diagnosed lung cancer report higher functional well-being (FWB) than men. Higher social support before diagnosis is associated with better social/family functioning (SWB) after diagnosis and, although limited by small numbers resilient personality was marginally associated with better general- and emotional quality of life shortly after diagnosis of lung cancer

The descriptive results of the level of social support and resilience showed that the younger population reported higher social support compared to older population while no other statistical significant associations were observed. Study of Chinese cancer survivors of different cancers, indicates that greater support from family and society was associated with higher quality of life (You et al, 2014). In addition, results indicated that quality of life had a stronger negative association with support from friends and a stronger positive association with support from society among younger survivors than among older survivors (You et al, 2014). When distribution of quality of life domains according to demographic and clinical characteristics were explored we saw that the older population and those diagnosed with lung cancer at advanced stages. Elderly patients often experience more symptoms of lung cancer which may indeed affect quality of life. In line with our findings, a study of newly diagnosed lung cancer patients showed that patients older than 70 years old experienced more lung cancer symptoms like cough, dyspnea and chest pain compared to patients younger than 70 years old (Gonzales-Barcala et al., 2014). In addition, study of lung cancer patients undergoing initial chemotherapy showed that with increasing age physical wellbeing decreased (Dai et al., 2017). Studies of the general population often report older age to be associated with decline in quality of life while the opposite has been reported in cancer populations (Holzner et al., 2004; Michelson et al., 2000). A study of quality of life among patients with advanced cancer revealed that older patients (over 60 years) and men reported better physical and emotional wellbeing than young patients and women (Zimmerman et al., 2011). Younger age may be associated with lower quality of life among cancer patients because of the traumatization of being diagnosed with a life-threatening disease at a young age (Zimmerman et al., 2011). In addition, younger patients often have greater family and community responsibility in comparison to the older (Wong et al., 2013; Zimmermann et al., 2011).

In our study functional wellbeing was significantly higher among newly diagnosed women compared to men but no other differences were found in other quality of life domains across the genders. In contrast, a result of a similar study among lung, breast and prostate cancer patients starting radiation therapy indicated that men reported higher quality of life compared to women (West et al., 2015). Indeed, female gender has previously been linked to higher risk of emotional distress in newly diagnosed lung cancer patients (Morrison et al., 2017). Furthermore, a study of patients with lymphoma, revealed that women reported significantly lower quality of life, in all domains except for social wellbeing (Pashos et al., 2013). The same was found in a study of the effect of gender on health-related quality of life in post-lobectomy lung cancer patients where men reported better quality

of life in all domains expect for social wellbeing (Chang et al., 2015) Finally, a study of determinants of quality of life among patients with various cancers indicated that men and older patients had better physical and emotional wellbeing than younger patients and women (Zimmerman et al., 2011).

In the current study we were not able to demonstrate a clear quality of life benefit after diagnosis of lung cancer by higher degree of social support, measured before diagnosis. Yet, social support seemed robustly associated with social wellbeing or family functioning after diagnosis when adjusting for age and gender ($p=0.01$). No other association was observed between social support and other quality of life domains which may due to low statistical power. Indeed, most previous studies have reported an association between social support and higher quality of life among lung cancer patients (Banik et al, 2017, Ellis et al., 2013, Luszczynska et al., Parker et al., 2003) Similarly, we did not observe any statically significant association between resilience and any of the quality of life measures. However, there was a trend of an association between resilience and emotional wellbeing and generic quality of life. Previous studies have generally suggested an association between resilience and quality of life among cancer patients and have for example suggested that patients with greater internal strength as a mark of resilience at the time of diagnosis report reduced distress and improved quality of life after diagnosis (Cohen et al., 2014a; Costa-Requena et al., 2015; Coughlin, 2008; Dubey et al., 2015; Jim et al., 2006). The main reason for the discrepancy of our results to previous findings is reasonably the lack of statistical power due to small cohort size.

Strength and limitation

This is the first prospective study in Iceland on quality of life of patients with newly diagnosed lung cancer.

The study protocol entails a meticulous measures of quality of life as well as social support and resilience. Yet, there are several limitations in the current study that need to be addressed. The obvious one is the small cohort size (35 patients) which resulted in a lack of statistical power to detect small or medium effect sizes. Although, the study had at the time recruited 67 patients diagnosed with lung cancer, only half of them participated in both assessment 1 and 2, for various reasons (figure 2) and could therefore not be used for the current analysis. Many patients with newly diagnosed lung cancer are in a state of shock and are therefore not ready to proceed with the heavy study protocol. This could influence our measures of quality of life; if only patients in the best “mental or physical” state finish their participation, we may be overestimating the quality of life in this patient group. Also, this might affect our measures of the associations between social support and resilience with quality of life in an undetermined manner. Even though the results of the current study did not show many statistically significant associations between social support and resilience with quality of life after diagnosis, the study was based on 35 patients and therefore had low statistical power to detect weak to modestly strong association and therefore difficult to compared to previously published data. Still, our data provide indications for that individuals with higher resilience and higher social support may report better quality of life.

In conclusion, the current study provides valuable important information on the quality of life of newly diagnosed lung cancer patients and the role of social support and resilience across quality of life domains.

Implication for nursing practice

Majority of lung cancer patients are diagnosed at an advanced stage and therefore have little curative options. The goal of treatment in this group of patients should emphasize maintaining quality of life (Raz et al., 2016; Shi et al., 2015)

The findings of the current study have important implication for clinical practices in oncologic care settings. Namely, they imply quality of life should be evaluated at baseline in lung cancer patients and followed during the course of the disease. Studies have indicated that information about quality of life in lung cancer patients undergoing treatment can provide a perspective on post treatment recovery as well as anticipated problems (Akin et al., 2010). Quality of life assessment provides useful information to clinicians, including the necessity of nursing intervention to improve quality of life and, possibly, survival in lung cancer patients.

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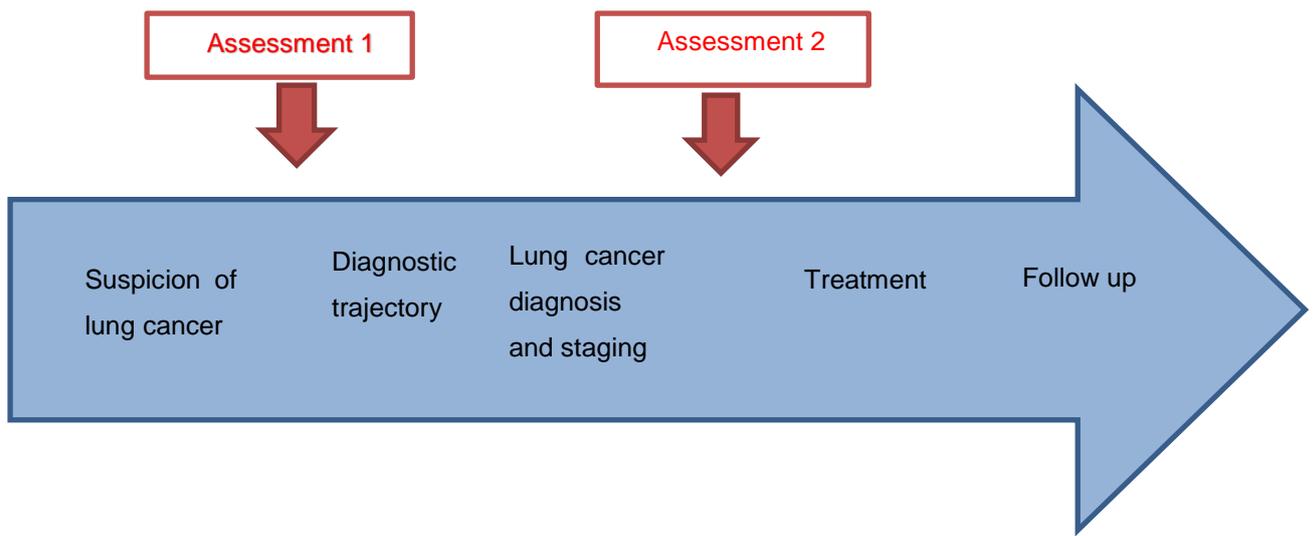


Figure 1. Diagram showing the process from suspicion of lung cancer to diagnosis in the fast diagnostic track at the University hospital of Iceland

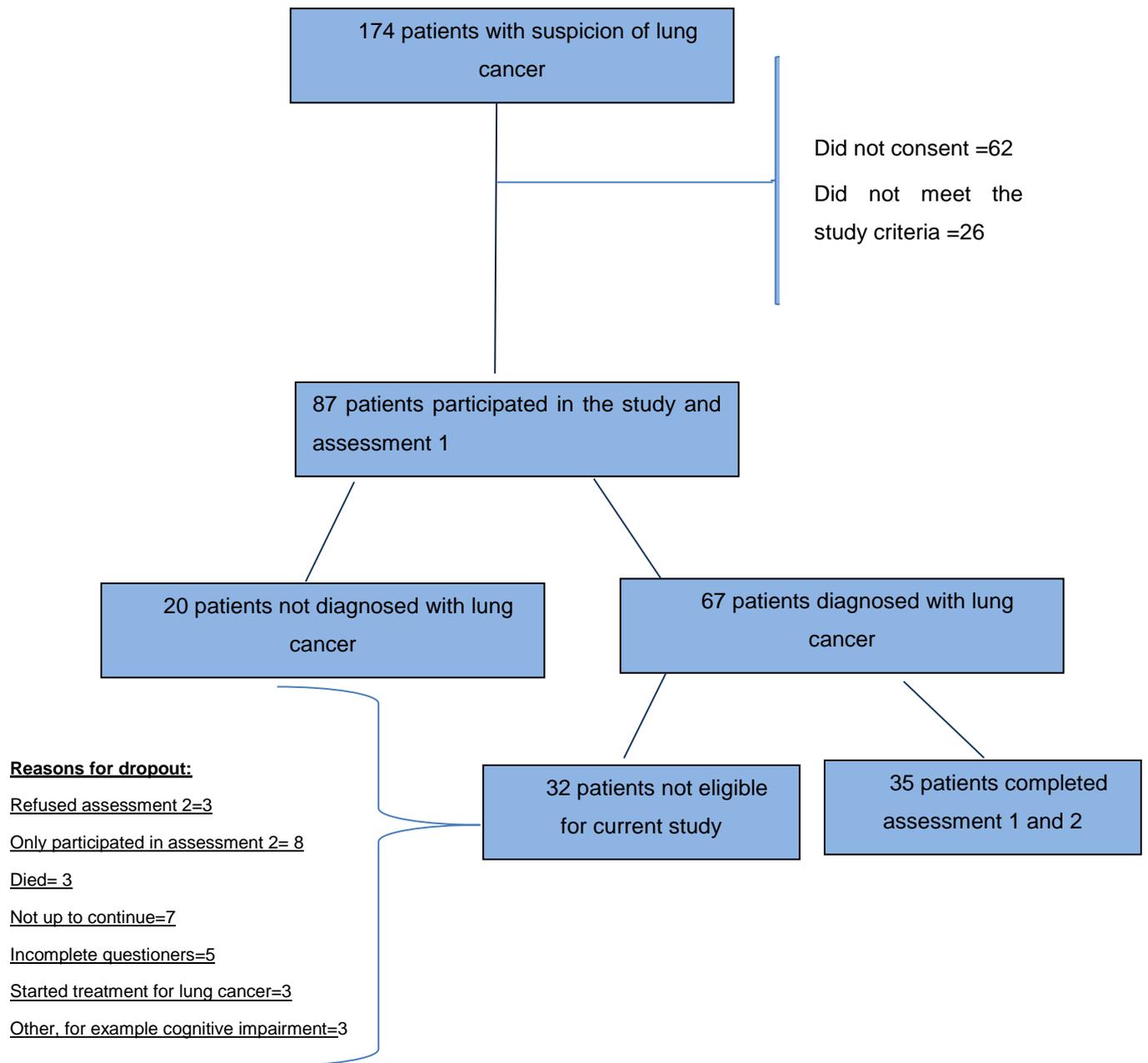


Figure 2. Eligible patients and reason for dropout

Table 1 Descriptive data on background and clinical characteristics of the patients finishing both assessments 1 and 2

	Mean	SD
Age (years)	71	±6.
Characteristic	N	%
Gender		
Male	18	51.4
Female	17	48.6
Spouses		
Yes	22	62.9
No	11	31.4
NA	2	5.7
Education		
Primary	20	57.1
Secondary	7	20
High	6	17.1
NA	2	5.7
Cancer stage		
I-II	19	54.3
III-IV	16	45.7

Table 2 Degree of social support and resilience according to background and clinical characteristic

Variable	Low/med social support n(%)	High social support N(%)	P-value *	Low resilience	High resilience	P-Value **
Gender			0.25	0.83		
Male n=18	9 (50.0)	8 (44.4)		8 (44.4)	9 (50.0)	
Female n=17	6 (35.3)	11 (64.7)		11 (64.7)	6 (35.2)	
Age group			0.02	1.0		
60-69 n=16	4 (25)	12 (75)		10 (62.5)	7 (37.5)	
+70 n=16	8 (50)	8 (50)		8 (50)	8 (50)	
NA=2						
Marital status			0.75	0.33		
Single n=11	4 (36.4)	7 (63.6)		6 (54.5)	5 (45.5)	
Not single n=22	10 (45.5)	12 (54.5)		12 (54.5)	10 (45.5)	
NA= 2						
Education			0.40	0.96		
Primary n=20	8 (40)	12 (60)		9 (45)	11 (55)	
Secondary n=7	2 (28.6)	5 (71.4)		4 (57.1)	3 (42.9)	
High n=6	4 (66.7)	2 (33.3)		5 (83.3)	1 (16.7)	
Cancer stage			0.89	0.90		
I-II n =19	9 (47.4)	10 (25.6)		10 (25.6)	9 (47.4)	
III-IV n=16	6 (37.5)	9 (56.2)		9 (56.3)	7 (43.7)	

*P value for social support and background and clinical characteristic

**P value for resilience and background and clinical characteristic

Table 3. Distribution of quality of life scores according to demographic and clinical characteristic

	PWB		SWB		EWB		FWB		FACT-G		LCS	
	\bar{X}	P	\bar{X}	P	\bar{X}	P	\bar{X}	P	\bar{X}	P	\bar{X}	P
Total (\pmSD)	16.8(5.8)		20.6 (3.9)		17.9(4.3)		19.6 (5.0)		75(12.5)		14.0(2.8)	
Men	17.0	0.86	19.8	0.23	18.3	0.52	18.0	0.05	73.1	0.40	13.1	0.11
Women	16.7		21.4		17.4		21.4		76.8		14.6	
Age 60-69	16.8	0.98	20.8	0.71	18.2	0.75	19.9	0.89	75.8	0.77	15.0	0.02
Age 70+	16.7		20.3		17.7		19.7		74.5		12.8	
Prim. Education	16.6	0.98	20.4	0.87	16.9	0.19	20.4	0.43	74.3	0.57	14.7	0.54
Sec education	16.8		20.3		17.9		17.6		72.6		12.1	
High education	17.2		21.3		20.7		20.7		79.9		14.0	
Cancer stage I-II	16.9	0.79	19.9	0.24	17.6	0.75	20.0	0.57	74.4	0.90	14.8	0.05
Cancer stage III-IV	16.4		21.5		18.1		19.0		74.9		13.0	

Table 4. Association between quality of life scores as a continues variable in relation to social support and resilience.

Social support								Resilience						
QOL dimensions	Intercept	β	CI*	P	Intercept **	β **	P **	Intercept	β	CI+	P	Intercept **	β **	P **
PWB	20.37	-0.21	-0.66-0.24	0.35	15.79	-0.19	0.43	10.27	0.18	-0.26-0.64	0.39	10.43	0.18	0.43
SWB	12.87	0.43	0.16-0.70	0.02	17.45	0.82	0.01	12.34	0.21	-0.08-0.50	0.15	10.55	0.19	0.20
EWB	15.51	0.12	-0.22-0.46	0.46	15.05	0.16	0.38	8.79	0.23	-0.13-0.60	0.19	8.87	0.26	0.09
FWB	19.58	-0.02	-0.40-0.40	0.99	15.03	-0.07	0.70	13.81	0.16	-0.27-0.60	0.43	13.63	0.11	0.57
LCS	13.6	0.09	-0.39-0.58	0.69	12.34	-0.01	0.93	15.11	0.03	-0.22-0.15	0.73	14.94	0.04	0.60
FACT-G	68.35	0.34	-0.61-1.30	0.46	46.08	0.34	0.49	45.21	0.80	-0.24-1.84	0.12	44.92	0.72	0.09

*Confidence interval for β

**Adjusted for gender and age group

