



# **Palliative care nurses facilitating the advance care planning discussion with patients newly diagnosed with lung cancer - patients' and families' experience**

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**Ritgerð til meistaraþráðu (60 einingar)**

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**HÁSKÓLI ÍSLANDS**  
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HJÚKRUNARFRÆÐIDEILD

**Palliative care nurses facilitating the advance care planning  
discussion with patients newly diagnosed with lung cancer –  
patients' and families' experience**

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Thesis for the degree of Master of Science

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**Samtal líknarhjúkrunarfræðinga við sjúklinga með nýgreint útbreitt  
lungnakrabbamein um áætlun um meðferðarmarkmið - Reynsla  
sjúklinga og aðstandenda**

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Ritgerð til meistaragráðu í hjúkrunarfræði

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## **Abstract**

The aim of advance care planning (ACP) is to allow patients to take an active part in decision-making, increase the quality of care and minimize the risk of providing treatment that is either futile or not wanted. While it is well recognized that an ACP discussion is an important part of palliative care, there is still a need to explore how it can become part of routine practice, ensuring a timely and person-centred discussion.

The purpose of the study was to explore the experience of patients newly diagnosed with advanced lung cancer and their family members of engaging in a discussion about ACP facilitated by palliative care nurses.

The study design was qualitative with a purposive sample, employing semi-structured interviews. The facilitation of the ACP discussion was added to an already established palliative support care service for newly diagnosed lung cancer patients in an outpatient clinic provided by two palliative care nurses. A framework for the ACP discussion was developed and an ACP booklet was translated and adapted. The ACP discussion took place in the second session with the support service and was followed by a research interview within two weeks.

Interviews were conducted with seven patients receiving the support service. Family members attended five of these interviews. Special focus was on the experience of the booklet, the timing of the discussion and the role of the palliative care nurse in initiating and leading the ACP discussion. Reflective field notes were written after each supportive care session and the research interviews. Interviews were transcribed verbatim and analysed using thematic analysis. Field notes were analysed with the aim of adding secondary data.

The findings indicated that opening the ACP discussion early in the care of the patient is acceptable and helpful even though uncomfortable. There seemed to be a tension for the patients between wanting to protect and to prepare their family for their death. The ACP discussion was a process and aided by the booklet. Even though, the patients did not write in the booklet it prompted a discussion and supported the nurse in initiating and having the discussion.

This study highlights that an ACP discussion, offered to patients newly diagnosed with lung cancer, may be acceptable and appropriate when structured as a part of a palliative care service. Palliative care nurses can be in a good position to facilitate the discussion in outpatient clinics. The framework, employed in this study, and the booklet were found helpful in opening the discussion.



## Ágrip

Markmið umræðu um áætlun um meðferðarmarkmið er að gefa sjúklingum tækifæri til að taka virkan þátt í ákvarðanatöku, bæta gæði umönnunar og draga úr því að meðferð, sem er gagnslaus eða ekki óskað eftir, sé veitt. Þessi umræða er mikilvægur hluti af líknarmeðferð en rannsóknir skortir á því hvernig hægt er að gera hana að eðlilegum hluta umönnunar sjúklinga sem fari fram tímanlega og sé miðuð að einstaklingnum.

Tilgangur rannsóknarinnar var að kanna reynslu sjúklinga sem eru nýgreindir með útbreitt lungnakrabbamein og aðstandenda þeirra af því að taka þátt í samtali við líknarhjúkrunarfræðinga um áætlun um meðferðarmarkmið.

Rannsóknarsniðið var eigindlegt með tilgangsrúrtaki og hálfstöðluðum viðtölum. Samtali um áætlun um meðferðarmarkmið var bætt við stuðningsþjónustu sem veitt er af tveimur hjúkrunarfræðingum í líknarráðgjafateymi fyrir sjúklinga sem eru nýgreindir með lungnakrabbamein og fá þjónustu á göngudeild. Viðtalsrammi var þróaður fyrir samtalið um áætlun um meðferðarmarkmið og blöðungurinn *Litið fram á veginn* þýddur og staðfærður. Samtalið fór fram í annað skiptið sem sjúklingurinn kom í stuðningsþjónustuna og rannsóknarviðtal var síðan tekið innan tveggja vikna.

Viðtöl voru tekin við sjö sjúklinga og aðstandendur tóku þátt í fimm þeirra. Áhersla var lögð á að skoða reynslu af notkun blöðungsins, tímasetningu umræðunnar og hlutverk hjúkrunarfræðingsins í því að opna og leiða umræðu um áætlun um meðferðarmarkmið. Líknarhjúkrunarfræðingarnir skráðu vettvangsnótur eftir viðtölin. Viðtölin voru greind með þemagreiningu. Vettvangsnóturnar voru notaðar til að fá viðbótarupplýsingar.

Megin niðurstöður benda til að það sé bæði ásættanlegt og hjálplegt að opna umræðuna um áætlun um meðferðarmarkmið snemma í sjúkdómsferlinu þó það geti verið óþægilegt. Sjúklingarnir vildu vernda fjölskyldu sína en á sama tíma undirbúa hana undir andlát sitt. Blöðungurinn hjálpaði til við umræðuna. Þrátt fyrir að sjúklingarnir fylltu ekki út í blöðunginn þá vakti hann umræðu og studdi hjúkrunarfræðinginn í því að opna samtalið.

Rannsóknin bendir til þess að það sé ásættanlegt og viðeigandi að eiga samtalið um áætlun um meðferðarmarkmið sem hluta af stuðningsþjónustu veitta af líknarhjúkrunarfræðingum fyrir sjúklinga með nýgreint lungnakrabbamein. Hjúkrunarfræðingar geta verið í góðri aðstöðu til að eiga þetta samtalið á göngudeildum. Notkun viðtalsramma og blöðungs voru hjálpleg við að opna umræðuna.





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# Table of contents

Abstract .....	3
Ágrip .....	5
Acknowledgements .....	7
Table of contents .....	9
List of abbreviations .....	11
1 Introduction .....	13
1.1 Palliative care .....	13
1.2 The definition of advance care planning .....	14
1.3 The development of advance care planning .....	14
1.4 Where do ideas of advance care planning come from? .....	16
1.5 Content and timing of discussion on advance care planning .....	16
1.6 Interventions involving advance care planning .....	17
1.7 Who should facilitate advance care planning? .....	18
1.8 Studies on the experience of ACP .....	20
1.9 Advance care planning documents – advance directives .....	21
1.10 The situation in Iceland .....	22
1.11 Summary .....	23
2 Methods .....	25
2.1 Aim of the study .....	25
2.2 Study design .....	25
2.3 The support service .....	26
2.4 The intervention – ACP added to the support service .....	26
2.5 The booklet Thinking ahead – what is important to me .....	27
2.6 Participants and recruitment .....	27
2.7 Data collection .....	29
2.8 Data analysis .....	30
2.9 Validity .....	31
2.10 Issues to consider in research in palliative care .....	32
2.11 Ethical issues .....	33
3 Results .....	35
3.1 Wanting to prepare and protect the family .....	35
3.2 Acceptable to open up the ACP discussion but not yet ready to take it further .....	37
3.3 Relevant, helpful and timely opening of ACP discussion .....	39
3.4 Having thought about it but not discussed it with anyone .....	40
3.5 Booklet helpful to open up the ACP discussion .....	41
3.6 Evidence from reflective notes – ACP discussion – easier than anticipated .....	41
4 Discussion .....	45
4.1 Implications for practice .....	48
4.2 Implications for research .....	49
Conclusion .....	51
References .....	53
Appendix .....	59

Appendix 1: The booklet <i>Thinking ahead – what is important to me</i> .....	61
Appendix 2: Framework for the support service.....	63
Appendix 3: Research interview guide.....	69
Appendix 4: Permission from the ethical board at Landspítali .....	73
Appendix 5: Permission from the Chief Medical Officer at Landspítali.....	75
Appendix 6: Letter of introduction .....	77
Appendix 7: Written consent .....	78
Appendix 8: Support from hospital chaplain.....	80

## **List of abbreviations**

ACP = Advance care planning

PC = Palliative care

HPCT = Hospital palliative care team

HCP = Health care professional

Keywords:

Advance care planning, palliative care, lung cancer, patient, family member, qualitative research.



# 1 Introduction

I believe that my experience of losing my father inspired me to study advance care planning (ACP). In my years as a nurse I have always been intrigued by communication with patients and their families. I was working as a nurse in oncology when my father died of cancer. Despite my degree in nursing and my experience caring for cancer patients I did not realize that he was dying before it was too late, that is a couple of days before he died. Therefore I did not get an opportunity to talk to him about what was going to happen and discuss all sorts of things with him and prepare. In hindsight, I am not sure if the health care professionals (HCPs) who were caring for my father realized that he was dying either, but that experience has made me feel that it is our obligation as HCPs to let the patient and the family know if we suspect the patient is dying, or at least offer this information to them. I have worked as a nurse in the Hospital Palliative Care Team (HPCT) for ten years. Most of the patients I meet have advanced disease and many of them are facing death. Many of the patients have not realized that their disease will probably lead to death for them in the near future and often they have not had the opportunity to prepare. One of the questions I routinely ask patients is what they know about their condition. They often lack information about their prognosis and the goals of treatment they are receiving. When I talk to clinicians they tell me they lack training and experience in talking with their patients about ACP. For me, this has highlighted the need to find ways of making ACP a routine part of the care we provide for patients with serious illness.

The aim of advance care planning is to increase quality of care, add to patients' autonomy and minimize the risk of providing treatment that is either futile or not wanted. By respecting patients' right to autonomy and giving them the opportunity to make informed decisions HCPs can help patients think about and make known their wishes regarding treatment and end of life care (Silveira, Kim, & Langa, 2010).

Starting from a personal and professional experience this thesis reports on a study where an intervention is tried that aims to open a discussion on ACP as a part of a support service for patients with advanced lung cancer. The study explores the experience of patients and their family members to see if this intervention is acceptable and appropriate as part of the support service.

In the introduction the researcher<sup>1</sup> will introduce ACP, which is one part of palliative care. She will describe how ACP is defined, where it comes from, how it has developed, interventions that have been tried, the timing and content of the interventions, who should discuss ACP with patients and the current situation in Iceland.

## 1.1 Palliative care

Palliative care has evolved from being end of life care for cancer patients into being an approach that is helpful for patients facing life-threatening illness from the time of diagnosis. The World Health Organization defines palliative care as an approach that improves the quality of life for patients with life-threatening illness and their families through the prevention and relief of suffering by means of

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<sup>1</sup> The researcher in this study is female and will be referred to as she.

early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2002). In guidelines on palliative care from the National Comprehensive Cancer Network (NCCN) it is stated that palliative care should be part of care of cancer patients from the time of diagnosis and through the trajectory of the disease concurrently with disease-directed, life-prolonging treatment and one part of providing palliative care is facilitating ACP (NCCN, 2014). Guidelines on palliative care from the Institute of Clinical Systems Improvement (McCusker M & M, 2013) recommend that patients in the early stages of serious illness who could benefit from palliative care should be identified and clinicians should facilitate ACP for all adult patients and their families.

Research has shown the efficacy of providing palliative care integrated with cancer care from diagnosis of cancer (Bakitas et al., 2009; Mack et al., 2012; Temel et al., 2010; Zimmermann et al., 2014). In a study conducted by Temel et al. (2010), patients with advanced lung cancer received specialized palliative care integrated with cancer treatment which resulted in better quality of life, improved symptoms of depression, less aggressive care at the end of life and better survival for patients in the intervention group compared to the control group. The support service provided in this study is based on the philosophy of palliative care and the service provided in the study by Temel et al. (2010).

## **1.2 The definition of advance care planning**

In clinical guidelines from the National Health Service in the UK, advance care planning is defined as a voluntary process of discussion about future care between an individual and their care providers (Henry & Seymour, 2008). The discussion should be about the individual's concerns and wishes, their personal values and goals for care, their understanding of their illness and prognosis, their preferences and wishes for types of care and treatment that may be beneficial in the future and the availability of such treatment. In clinical guidelines from the National Comprehensive Cancer Network (NCCN)(2014) the purpose of ACP is to increase patient's independence in decision-making about treatment. The hope is that the result will be that the patient's wishes are better met and there is less of a burden for their families when the patient is incapable of making decisions.

## **1.3 The development of advance care planning**

Today, because of new technology and treatment options patients live longer with life-threatening disease than they ever have before. These changes do not necessarily lead to better care or quality of life. However, new treatments and technology are expensive and sometimes are not what the patient wants (Gillick, 2004; Street & Ottman, 2006). It is therefore very important that patients have an opportunity to speak with their family and HCPs about their wishes and the expectations they have regarding treatment and what is important to them. This is the essence of advance care planning.

To better understand the development of ACP it is helpful to look at how health care has developed in the last few decades. At the beginning of the sixties cardiopulmonary resuscitation was first developed and began to be used in hospitals in developed countries. At the same time there was great development in life-prolonging treatment, such as medical ventilators, that made it possible to



keep people that had been resuscitated alive. The results were often not what was hoped for and the patient died or suffered severe brain damage. The question of who should be resuscitated and put on a ventilator was raised. Following on from this, patients started to express a desire to take part in the decision-making and they started to document their wishes concerning life-prolonging treatment. This was the start of the development of documenting patient's wishes in the form of advance directives (Advance Care Planning, 2015).

The development started in the United States and other nations followed. In the US the Patient Self-Determination Act was passed in 1990 and this required hospitals and health care facilities to provide patients with written information on their right to decide on whether they wanted medical treatment or not and the right to make advance directives (Wenger et al., 1994). Research done on the use of advance directives was disappointing and many HCPs started to believe that they were not helpful. The SUPPORT study that was done after the legislation was implemented, was a large intervention study where trained nurses met patients, their family, physicians, and hospital staff on several occasions to elicit preferences for care, improve understanding, and facilitate ACP and patient-physician communication. This study did not show improvement in the incidence or timing of written do-not-resuscitate orders, physicians' knowledge of their patients' preferences for cardiopulmonary resuscitation or communication between the patient and the physician (Connors, Dawson, Desbiens, et al., 1995), demonstrating that the document-driven approach to ACP was not working (C. A. Robinson, 2011). However more recent studies have shown more positive results and it seems that advance directives that are written in the context of ACP which include a discussion on the values and goals of the patient have been receiving increasing attention in recent years (Janssen, Engelberg, Wouters, & Curtis, 2012). Barnes et al. (2011) suggest that ACP gives patients opportunities to consider, discuss and make plans for their care in the future with HCPs and sometimes their family. Such a discussion can entail making advance directives or selecting a surrogate decision-maker if the capacity to make decisions is lost.

It is hard to predict what patient's wishes will be for life prolonging treatment, such as ventilator support and cardiopulmonary resuscitation. It is necessary for HCPs to discuss with patients what they would want, especially when the patients have diseases that could call for certain treatments (Janssen, Spruit, Schols, & Wouters, 2011). In recent years, the emphasis in advance care planning has developed into being a process that takes place in repeated communication with the patient, the family and the HCP. The discussion is aimed at helping patients and families develop prognostic awareness and an understanding of the illness. Part of the discussion should be that the HCP makes a recommendation about a plan of care based on the patient's goals and values (Jacobsen, Robinson, Jackson, Meigs, & Billings, 2011). It is acknowledged that under some circumstances certain interventions such as cardiopulmonary resuscitation are unlikely to benefit the patient and such interventions should not be offered to patients because they may interpret the option as an indication of hope for improvement. It could really be burdensome for the patient to be offered a choice that is

very unlikely to be helpful. By recommending a certain plan of care the HCP shares the burden of decision-making with the patient and his<sup>2</sup> family (Jacobsen et al., 2011).

In recent years the emphasis in ACP has been on preparing patients to make decisions about treatment rather than deciding what kind of treatment they want in the future (Patel, Janssen, & Curtis, 2012; Sudore & Fried, 2010). The definition of ACP has, therefore, evolved from a narrow definition of writing advance directives into a process that begins at diagnosis of a serious illness and continues until the time of death (Lorenz, Rosenfeld, & Wenger, 2007) and focuses on discussing patient's understanding of illness and values and goals concerning future care (Henry & Seymour, 2008).

## **1.4 Where do ideas of advance care planning come from?**

Advance care planning is connected to ideas of patient's self-determination and informed consent and is in a way a response to the paternalism that had been dominant in health care (Kring, 2007). Arnason (2003) argues that decisions on treatment should be taken in consultation with the patient and should be built on mutual trust where the patient is informed of his condition and possible treatments. He talks about the importance of preparing for this discussion and that it is important to make sure the patient understands the information he receives. Of equal importance is to provide psychological support that is based on understanding, empathy, and being honest about the situation. If that is not done it cannot be said that the patient has given an informed consent. The goal of the discussion is to give information, listen to the patient's wishes and values, and make a recommendation. The HCP partners with the patient to make mutually acceptable decisions (Kring, 2007)

It could be argued that self-determination as it is defined serves only a few patients that are diagnosed with serious illness. Some patients do not want self-determination nor do they find it important, and they define it in a different way. Some patients prefer to think of the goal of treatment, rather than whether they want this treatment or another one. Certain characteristics of patients determine what opinion they have on self-determination, for example, physical and mental capacity, age, race, cultural background and wanting to protect their family (Arnason, 2003). To be able to make ACP better for a more varied group of patients, certain factors need to be considered. It is important to increase flexibility in discussing ACP. There is also a need for improvement in the communication between HCPs and families when the patient cannot take part in decision-making, where it is made easier for families to take part in the decision-making process and they are put under less emotional pressure (Winzelberg, Hanson, & Tulskey, 2005). Patients have varied needs regarding ACP. Some patients have spent a great deal of time considering what they want, some need more information on what their options are, and some patients will simply not talk about it.

## **1.5 Content and timing of discussion on advance care planning**

Studies have been conducted to determine who should have an advance care planning discussion with patients and families and when and how it should be carried out. The studies have shown that it is

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<sup>2</sup> The tradition in Icelandic is to use the pronoun he when writing about the patient or participant.

important that the HCP has a relationship with the patient; that the HCP should find out what the patient understands about his condition and how much information he wants to receive, and there should be negotiation on who should be present at the discussion and who should provide the information (Clayton, Butow, & Tattersall, 2005). A review article (Barnes et al., 2012), that analyses studies on interventions that have been developed to have a discussion on ACP reveals that ideally the discussion should take place during several interviews with a HCP who has been trained to have this discussion and has enough time to answer questions. Timing was found to be likely to affect the acceptability and effect of the discussion, and the discussion might best be initiated after the disease had recurred (Barnes et al, 2007). According to guidelines of the National Health Service in the UK on ACP (Henry & Seymour, 2008) the discussion should take place following diagnosis of a life-threatening disease, when there is a shift in the focus of treatment, when individual needs are being assessed or when there are repeated hospital admissions. The discussion should be directed more towards goals of treatment rather than individual interventions, and HCPs need to be sensitive to the patient's wellbeing during the discussion (Tulsky, 2005). The discussion has to be tailored to the individual to avoid taking away hope, and it is of great importance to document the patient's wishes (Barnes et al., 2012). Also, patients should be offered opportunities to reconsider previous decisions that they have made and that have been documented ((NICE), 2004; NCCN, 2014).

Patients want as much information about their condition as possible even though the information is unfavourable (Barclay, Blackhall, & Tulsky, 2007). However, what they prefer to know the least about is their prognosis and studies in the UK indicate that even though patients want honest information about their condition they do not want unambiguous information on prognosis (Innes & Payne, 2009). Discussing ACP is hard due to the fact that patients do not want to get much information on prognosis combined with the fact that many patients are poorly aware of their condition. Patient education and disclosure needs to take account of the patient's needs and wishes, and an opportunity for discussion can only be offered, not forced. In circumstances where the patient is not willing to discuss future treatment or get information on prognosis, the discussion needs to be on his values and wishes, for example whether there is anything the HCP needs to know about the patient to be able to care for him, and with whom the HCP should discuss the patient's condition if the patient becomes too ill to decide for himself what he wants (Barnes et al., 2012).

As regards the timing of the ACP discussion, it has been pointed out that such a discussion should at least take place when the HCP would not be surprised that the patient would die within a year (Davison, 2008). A study by Detering, Hancock, Reade, and Silvester (2010) showed that patients' wishes at the end of life were more likely to be respected if the patients had taken part in a discussion on ACP. Their families also experienced less stress, anxiety and depression. However today these conversations often take place in the acute setting in a hospital or not at all (Mack et al., 2012).

## **1.6 Interventions involving advance care planning**

In many countries policies and clinical guidelines on ACP have been put forward and many interventions have been developed aimed at making ACP a normal part of care for patients with life threatening diseases. One of the oldest and most tried intervention was developed in La Crosse,

Wisconsin in the US twenty years ago. It is called *Respecting Choices* and is aimed at the entire community. The purpose is to change people's attitudes and open up a discussion on end of life care and people's wishes at that time (Gundersen Health System, n.d.). This model contains patient education, training for HCPs, coordinated documentation and coordination within the health care system in a particular region (Moorman, Carr, Kirchhoff, & Hammes, 2012). The model's success shows that ACP involves much more than documenting advance directives or selecting a surrogate decision-maker (Gillick, 2004). Hammes and Rooney (1998) demonstrated the effectiveness of this intervention, where 85% of people who died in the period that was examined had a written advance directive, which was a much higher percentage than before the intervention (15%). *Respecting Choices* has been implemented elsewhere in the US and in Australia. It is also being implemented in Germany, Spain and Singapore, and Canadians have used it as a model (Gundersen Health System, n.d.). In the UK policies and clinical guidelines on ACP have been put forward and much effort has been put into education and training for HCPs to have this discussion with patients and their families (Henry & Seymour, 2008).

Barnes et al. (2012) review article revealed important issues concerning the success of the advance care planning interventions. The HCPs need to be trained to facilitate the discussion, the patient's understanding of his condition needs to be improved, the discussion should preferably take place over a number of meetings, and documentation should be part of the intervention. Various ways to make ACP a normal part of caring for patients have been tried. One way is to educate and train HCPs both as a part of their formal education and also as a part of continuing education.

Intervention studies of ACP show that ACP increases the documentation of treatment goals and discussion on end of life care and, there is improved concordance between preferences for care and delivered care and it may improve other outcomes, such as quality of communication (Houben, Spruit, Groenen, Wouters, & Janssen, 2014). Patients want to discuss care at the end of life and their wishes for that care. But often ACP is not provided and this discussion does not take place (Janssen, Spruit, Schols, & Wouters, 2011). The interventions most likely to facilitate an ACP discussion were those where the HCPs who were the primary carers for the patients had the conversations and where the HCPs were provided with a structure that supported them in how to do it (Lund, Richardson, and May, 2015). ACP not only benefits patients but can also reduce stress, anxiety and depression in family members (Detering et al., 2010; Silveira et al., 2010). According to the American Cancer Society (ASCO), failing to have a discussion on ACP can lead to increased psychological distress, medical treatments incongruent with personal preferences, use of burdensome and expensive health care resources with limited therapeutic benefit, and a more difficult bereavement (National Cancer Institute, 2015).

## **1.7 Who should facilitate advance care planning?**

In many of the interventions that have been studied, certain HCPs are specially trained to facilitate ACP. These HCPs are usually not the providers providing primary care to the patients. In the intervention *Respecting Choices* the facilitators for the discussion are HCPs that are trained to have this discussion, mostly nurses and social workers. These HCPs do not have a previous relationship

with the patients. In the US it is more common that HCPs, who facilitate ACP, have no previous relationship with the patient. In the UK the HCPs who have the discussion with the patients are their primary HCPs. There is an ongoing study in the US (Bernacki et al., 2015) on an ACP intervention where clinicians have been trained to have a discussion on ACP with their patients using a structured guide. The trigger to start the conversation is the surprise question when the clinicians are asked whether they would be surprised if the patient died within a year.

Research shows varied results when patients are asked with whom they would like to discuss these matters. In a study of Barnes, Jones, Tookman, and King (2007) patients think that physicians who are treating them are not well suited to have this discussion and they prefer HCPs that have been trained to have this discussion and have good communication skills. Clinical nurse specialists are mentioned as well. Nurses spend much time with the patients and serve as their advocates in the complex environment of health care. Therefore, nurses can be in a good position to take part in a discussion on ACP. The American Nurses Association (ANA) put forward a position statement in 1991, shortly after the Patient Self-Determination act was imposed, that stated that nurses have an important role in this discussion. A revised statement from ANA (2012) stated that the role nurses have is to educate patients and families on possible treatments, and that patients have the right to stop treatment and to document advance directives. Nurses should also encourage patients to think about their preferences at the end of life and should support patients and their families in discussing the goals of treatment with their physicians. Furthermore, nurses should provide other HCPs with information about anything that could influence decision-making at the end of life, and should be patient advocates. It can be said that at least nurses should take care of patients' interests by evaluating their understanding of their condition and decisions that have been made, and they should ensure that patients and families get opportunities to discuss ACP, for example by suggesting a family meeting (Lachman, 2010).

In line with position statements, research has shown that nurses are prepared to participate in discussions on end of life and even initiate them (Sulmasy, He, McAuley, & Ury, 2008). However, there are still many obstacles preventing nurses taking an active part in these discussions. Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, and Bradley (2005) showed that the main reasons that nurses did not discuss prognosis and palliative care with patients were that the patients and their families could not accept the fact that the patient was dying, the patient died suddenly or the patient's condition deteriorated, the physician was uncertain in his position or the nurses wanted to maintain hope.

In the UK Robinson et al. (2012) had focus groups with HCPs, working in palliative care and care for patients with dementia, on ACP. The findings revealed uncertainty surrounding several aspects of ACP. Among them were that the HCPs thought that ACP was a good idea in principle but difficult to implement. They did not want the discussion to be taken lightly and to be made a tick box effort because they thought the discussion should be individualized. The discussion should be an ongoing process throughout the illness trajectory where the patient and his family members would receive information on their disease and condition and get an opportunity to discuss their wishes and needs. In the same study specialists in PC, some GPs, and nurses working in home care felt that it was their

responsibility to have this discussion but others felt that it was not, because of lack of time and training. Within the Icelandic context there have been no studies on the role of nurses in ACP. However, in a focus group conducted by the researcher in his Master's studies, prior to this study with seven clinical nurse specialists in various serious illness specialities working at Landspítali, the participants agreed that it was a part of their job as nurses to participate in facilitating the ACP discussion with patients. They also thought that nurses needed more training to facilitate this discussion and some of them said that they did not trust just any HCP to have this conversation (Olafsdóttir, 2013). Baughman et al. (2012) conducted a study in the US where they looked at how nurses and social workers that care for patients in the community defined ACP and how they saw their role in this discussion. They said that their patients had limited knowledge and understanding concerning ACP and that they were afraid to talk about issues concerning death and their wishes at the end of life. The participants defined ACP broadly and only a part of ACP was the writing of advance directives. ACP should entail discussion on social and medical issues, ongoing communication and education. They felt that they needed to inform the patients of their right to decide for themselves what kind of treatment they received. They looked at themselves as patient advocates who should make information on patients' wishes available. A recent systematic review and synthesis of qualitative studies of nurses' views regarding implementing ACP (Ke, Huang, O'Connor, & Lee, 2015) showed that, in general, nurses believed that they were in a good position to facilitate ACP discussions but at the same time they highlighted the need for education and support for nurses to prepare them for that role.

## **1.8 Studies on the experience of ACP**

One study similar to this one (Horne, Seymour, & Shepherd, 2006) piloted an ACP intervention. Fifteen patients took part in an ACP discussion with their lung cancer nurse and then nine patients were interviewed to gain their views on the ACP discussion. Six of them had family members present. The findings showed that they had varied reactions to engaging in the discussion. Most reported that they felt better after discussing their preferences for end of life care and were happy to have their wishes recorded. Other key findings were that the nurses' characteristics aided the discussion and the patients appreciated the information and explanation they were given. The same researchers did another study (Horne et al., 2012) with the aim of exploring what perceptions patients with advanced lung cancer and their family members had about discussing and planning future care and treatment. They conducted semi-structured interviews with 25 patients and 19 family members using grounded theory. Their main results were that many of the patients did not feel ill and therefore did not see the need to discuss the future; they felt that it was a hard thing to talk about and wanted to put these thoughts aside. The patients wanted to carry on as normal but concern for the family was the main factor that influenced them to plan the future, and then they were planning for death and not what should be done when they were dying. At the same time the patients were worried about upsetting the family by making plans. Most of the patients had little recall of discussing ACP previously with their physician.

Simon, Murray, and Raffin (2008) conducted a study in Canada looking at the experience patients with end stage renal disease have of discussing ACP. The study took place about a month after the discussion. The discussion was facilitated by a HCP that had been trained to facilitate ACP based on the *Respecting Choices* model and did not have a prior relationship with the patients (N=6). The main results were that the participants experienced the process as a positive thing. After the process that contained both a discussion with the facilitator and their physician, and work on an ACP workbook, the patients felt comfortable that they had reduced family stress and addressed their concerns about living in a burdensome state and they had gained peace of mind from the process.

Barnes et al. (2011) conducted an analysis of dialogues between patients with advanced cancer and ACP facilitators. Most of the patients had not discussed ACP previously with HCPs or their family. Their main concerns were experiencing difficult symptoms and how their family members' would cope. Some of the patients wanted more accurate information and were unaware of their options for care. Many of them thought that their physicians should initiate a discussion on ACP but felt that they were reluctant to do so. Some of the patients felt that it was not yet the right time to start this discussion.

Johnson, Butow, Kerridge, and Tattersall (2015) conducted a systematic review of research on the experiences and perceptions of patients, families and HCPs regarding ACP for cancer patients. Their findings showed that the family was both a motivator and a barrier to ACP, that ACP might provoke fear and distress and that autonomy was conceptually complex and had different meaning to different people. For some, including family in ACP raised concerns over upsetting the family and others had difficulties raising the issue with their family, but the family was also seen as a motivator for the discussion because the patients thought that it could ease the burden for the family. ACP was viewed as desirable but there were fears that it could be distressing either for the patient or the family, and patients and family identified a tension between wanting to discuss ACP and wanting to go on with life as usual. Although it was common that both patients and HCPs expressed fears that ACP would destroy hope, the results suggested that this was not necessarily the case. Patients rarely discussed ACP in order to have control over treatment decisions. Instead, they wanted to discuss the social, psychological and emotional issues that arise when death is approaching. The results of the study indicate that HCPs look at ACP as a decisional tool but in fact its utility is more a family-centred and social process. Therefore where emotional and social factors that are necessary for successful ACP are missing, patients will not be able to participate in ACP and it will only function as a means for HCPs to document limitations to treatment.

## **1.9 Advance care planning documents – advance directives**

Writing advance directives is rarely done and does not always benefit the patients because their wishes are not respected or what the surrogates decide is not in congruence with the patients' wishes. On the other hand research shows that advance directives can be a tool to start a discussion on ACP where the patient's wishes and goals for treatment are discussed, preferably with a family member present (Barclay et al., 2007). The documentation of wishes to forego treatment such as cardiopulmonary resuscitation should only be a small part of the discussion and the patients should have opportunities to change their mind (Barnes et al., 2007). Many types of document are used, and

it is considered vital to be able to document the wishes the patient has about that direct what treatment should be used at the end of life and who should make medical decisions for the individual if he is too ill to make them himself. Other documents provide information to family and HCPs about what is important to the individual at the end of life, where he would prefer to die, and what he would like his funeral arrangements to be. A document called the *Physician orders for life-sustaining treatment (POLST)* is used in 44 states in the US and documents patient's wishes about treatment. The *POLST* is a legal document that is filled out by the physician and signed by the patient, and is only for patients with serious illness ([www.polst.org](http://www.polst.org)). *Five wishes* is another document developed in the US where patients themselves can write their wishes and values to share with their family and HCPs ([www.fivewishes.org](http://www.fivewishes.org)). There are several different documents used in Europe as well, and the legislation varies between countries in Europe.

## **1.10 The situation in Iceland**

In Iceland, clinical guidelines on palliative care were issued in 2009 by Landspítali, the National University Hospital of Iceland. These state that palliative care is appropriate after diagnosis of a life-threatening disease and that it is best practice for the physician that is treating the patient and knows him to have a timely discussion about the goals of treatment and decisions concerning foregoing any treatment. By doing that decisions made in acute circumstances can be avoided. ACP should be started early in the course of serious illness (Landspítali, 2009). According to the Patients' Rights Act no. 74/1997 in Icelandic legislation, the patient has the right to information regarding medical condition, prognosis, treatment, risks and benefits and consequences of refraining from treatment. The right of the patient to decide whether to accept treatment should be respected. In 1989 Jonsson wrote an article about the need for making guidelines for HCPs on how to make decisions on limiting treatment and that doctors should discuss this with their patients. In 1995 a survey was conducted among doctors and nurses in which they were asked about their perspective on limiting treatment at the end of life. Their general opinion was that patients' wishes should be honoured when considering limiting treatment (Valsdottir, Jonsson, Arnason, & Helgadóttir, 1997).

In 2005 the Directorate of Health in Iceland issued an advance directive document, called *Lífsskrá*, in which individuals can document their wishes for treatment at the end of life. The document addresses two important issues; what should be done at the end of life and choosing a surrogate should the individual become incapable of making decisions. The role of the surrogate is to take part in discussions about treatment choices for the individual. The stated purpose of this advance directive is for dignified death and for the family to be as content as possible when the individual has decided not to have treatment or tests done that do not give a realistic hope for cure. The advance directive is not mentioned in Icelandic law and therefore has no legal value. The document needs to be signed in four copies, one for the individual, one for the Directorate of Health, one for the surrogate and the last copy should preferably go to the individual's primary physician or other physician (Landlæknir, 2005). The document was accessible in the Directorate of Health during office hours. It seems that few people in Iceland know of the existence of the advance directive and even fewer have made one. In February 2015 the Directorate of Health issued a statement that the Directorate would no longer be



offering people the choice to make their wishes known using the *Lífsskrá* document and that people should make their wishes known to their family and their primary physician (Landlæknir, 2015). The discontinuation was not explained.

There has been no research on how this discussion occurs in Iceland but there are indications that they occur late in the disease trajectory, at the end of life or not at all. The experience of the researcher related to her own practice area is that limitations to treatment are written a few hours or days before death or not at all. Similarly a study in the US showed very high rates of signing DNR on the last day of life (Walling, Asch, Lorenz, & et al., 2010)

## **1.11 Summary**

Advance care planning is a voluntary process of discussion about future care between patients and HCPs and is part of palliative care. The discussion should be about concerns and wishes of the individual, personal values and goals for care and the individual's understanding about illness and prognosis. ACP has proved to be beneficial for patients and family members and various interventions have been developed to make ACP part of care for patients. However, it is not demonstrated clearly in a practical way in the literature how or when ACP should be facilitated or which HCP should do it. ACP interventions have not been implemented or studied in Iceland.

The focus of this research is to study the patients' and family members' experience of discussing ACP as a part of the support service for patients newly diagnosed with advanced lung cancer. The aim is to find out whether patients and their families find opening the discussion acceptable in this way, whether the timing of the discussion is appropriate and whether a booklet helps with having this discussion. Because facilitating the ACP discussion in this way, is being tried for the first time in Iceland it was important to find out whether opening the discussion was acceptable, as perceived by patients and family members, to see whether it is justifiable for the nurses in HPCT to proceed with including the ACP discussion in the support service for patients with newly diagnosed lung cancer.

The research question is:

What is the experience of patients and families of palliative care nurses facilitating the discussion on ACP with patients newly diagnosed with lung cancer and their families using a specific framework for the support service and the booklet *Thinking ahead – what is important to me* as a part of the support service provided in an oncology outpatient unit?



## **2 Methods**

This study was part of a larger study researching the effects of a support service offering early palliative care to patients newly diagnosed with advanced lung cancer, and provided by the Hospital Palliative Care Team at Landspítali, the National University Hospital.

### **2.1 Aim of the study**

The aim of this study was to explore the experience of opening a discussion on advance care planning as a part of a support service provided by the HPCT for patients newly diagnosed with advanced lung cancer.

### **2.2 Study design**

Qualitative methods were used to explore the experience of opening this discussion because this was the first time in Iceland facilitating a discussion on ACP has been tried. It was therefore essential to get an idea of whether the discussion was considered acceptable and timely as perceived by patients and family members. Using qualitative methods gives a better understanding of the experience for patients and their family members than using quantitative methods (Polit & Beck, 2012).

The HPCT had been providing the support service for patients with lung cancer for about a year and was looking at ways to open a discussion on ACP. To get insight into whether it is acceptable to open the discussion in this way using the booklet and the framework of the support service at this point in time, the HPCT wanted to carry out a study that would highlight the patients' and family members' experience. ACP is a new concept in Iceland and has not, to the researcher's knowledge, previously been implemented in any form in Iceland. This was a pilot of facilitating an ACP discussion with a few patients to gather data on whether it is acceptable to open the discussion in this way and therefore qualitative methods were appropriate for study design. The focus of the research was to study the patient's and their family members' experience of opening the discussion and for that purpose qualitative methods are ideal (Polit & Beck, 2012). Qualitative research is often concerned more with authenticity rather than with reliability where the aim is to gather an authentic understanding of people's experience, and it can be argued that asking open-ended questions is a way towards that end (Seale & Silverman, 1997). Interviews were selected as a method of data collection because they are useful for collecting sensitive information and they provide a flexible approach for exploring people's experience (DiCicco-Bloom & Crabtree, 2006; Jonsdottir, 2012). It was therefore decided to conduct semi-structured interviews to explore the experience, using an open-ended question, and then probing more into the issues as needed. It was also decided to let the palliative care nurses write reflective field notes after each ACP discussion and the researcher after the interview. The decision to use reflective field notes was made to let the researcher document her observation of patients' and family members' non-verbal expressions in the interviews and how she herself was feeling during the interviews (Jonsdottir, 2012). Reflective field notes were written to obtain a more complete picture of a complex issue (Tobin & Begley, 2004), and can add to the credibility of the study (Krefting, 1991).

## **2.3 The support service**

The support service is specialized palliative care provided by the HPCT generally to patients with advanced lung cancer, and has been in practice since March 2014. The overall purpose of the support service is to improve quality of life, reduce symptoms and have a discussion with patients about their goals and expectations for future treatment. The support service is integrated with standardized cancer care at the outpatient oncology unit at Landspítali. Patients are recruited into the support service by the nurse navigator for lung cancer patients, who identifies patients for whom the service would be appropriate. The support service starts with the patients meeting a palliative care nurse from the HPCT four to six weeks after meeting the oncologist in a diagnostic interview. The patients then meet the nurse every four to six weeks after the initial meeting. The service is provided at the outpatient oncology clinic. One hour is scheduled for each meeting. The nurses in the HPCT follow a framework for the support service during each meeting that is based on the philosophy of palliative care and the intervention provided by Temel et al. (2010) (appendix 2). During each meeting they conduct a purposeful assessment of symptoms, distress and needs and give recommendations for symptom management and coordinate care on the basis of the individual needs of the patient. The nurse contacts the physician of the HPCT for advice about medication and the physician then prescribes it if needed. Two tools are used to evaluate symptoms and distress, the Edmonton Symptom Assessment Scale (ESAS-r) and the Distress Thermometer (DT). Two nurses provide the support service. One is the researcher who has long experience in palliative care, and the other is a clinical nurse specialist in palliative nursing, with years of experience. As described in the introduction, it is now recommended that ACP should be a part of palliative care services. Based on evidence from the literature the HPCT decided to include an ACP discussion into the support service provided to the patients who have a life-threatening, incurable condition with a limited life expectancy. This study explores patients' and family members' experience of an ACP discussion. In order to facilitate the ACP discussion, the framework for the support service was expanded to include an opening to an ACP discussion, and a booklet called *Thinking ahead – what is important to me* was translated and adapted.

## **2.4 The intervention – ACP added to the support service**

The intervention consisted of adding to the existing framework for the support service that the palliative care nurses facilitated the ACP discussion using a booklet to aid the discussion to make it a part of the support service.

In the first session with the support service the nurse assessed the patient's understanding of his disease, prognosis and goals of treatment. They then discussed how treatment decisions were made and the patient's ways of coping. In reviewing the framework for the support service a discussion on ACP was added. In the second session after having assessed symptoms and distress and made plans for care, the nurse asked the patient for permission to start a discussion about the future. The nurse explained that this discussion is a normal part of the support service and that all patients are offered it. The patient was told that it is important to discuss the future when things are going well because it gives him and his family an opportunity to think about the future and prepare in case things get worse.

It was explained that discussing the future now did not mean that the disease was getting worse but it was a serious illness and it would be good to have a plan in case things do not go as hoped. After getting permission from the patient to proceed with the discussion the booklet *Thinking ahead – what is important to me* (appendix 1) was introduced, with particular emphasis on giving the patient an opportunity to discuss and write down his wishes for future treatment. The nurse showed the patient and his family member each section of the booklet and explained as needed. The patient could write in the booklet his wishes regarding future care and what was important to him at the end of life. The booklet was not a legal document and was something the patient could keep for himself, and it was his decision to allow the nurse to write something in the electronic medical record that he would like HCPs to know.

In the third session with the support service, the ACP discussion was continued by bringing the subject up again, asking whether patient and family had discussed ACP further at home, and whether the patient had written anything in the booklet. The patient and family member were given an opportunity to discuss the matter further and ask questions. The nurse asked if there was anything the patient would like to be put in his electronic medical record.

## **2.5 The booklet *Thinking ahead – what is important to me***

After examining several documents the researcher decided on using a booklet developed by Strathcarron Hospice in Scotland. The booklet has a useful focus asking questions both on the patient's perspective regarding future care and personal decisions regarding end of life. The booklet was developed to facilitate a discussion on ACP and give the patient an opportunity to convey his wishes for end of life care. The booklet is called *Thinking ahead – what is important to me*. In it the patient can write what he wants others to know about him, what is important to him and what his preferences are for future care. He can write down where he would prefer to be cared for at the end of life, if he has made a will or advance directives and his wishes for life-sustaining treatment. He can also make a checklist for important issues that he would like to share with his family and how he would like his funeral arrangements to be. In the booklet patients are reminded to review regularly what they have written in the booklet so that what is written reflects their wishes. The aim of the booklet is to facilitate a discussion between the patient, his family and HCPs and it is not a legal document. Based on a review of a few documents that have been developed to aid ACP discussions, this booklet was translated and adapted to use to support the ACP discussion within the support service provided by the HPCT (appendix 1).

## **2.6 Participants and recruitment**

The sample was a purposive one, which means that the selection of participants was based on the purpose of the study (Polit & Beck, 2012) which was to explore the experience of opening a discussion on ACP with patients with an advanced progressive disease and limited life expectancy. The literature suggests that ACP discussions should take place for patients with a limited life expectancy when the clinicians would not be surprised if the patients would die within two years (Davison, 2008). Hence it was decided that the patients group that would fit well with the purpose of the study would be patients

receiving the support service due to them being newly diagnosed with advanced lung cancer. The inclusion criteria were; that the participants were receiving the support service because they had been newly diagnosed with advanced lung cancer, and participants had to be older than 18 and speak and understand Icelandic. All patients that were receiving the support service provided by the HPCT at Landspítali from December 2014 until September 2015 were invited to participate. Of 21 patients who were receiving the support service during the research period 12 agreed to participate in the study and nine declined.

In the beginning, the study was introduced to the oncologists and nurse navigators by email. A meeting was held with the head nurse and nurse navigators to introduce the study and get their cooperation to find candidates for the study. The researcher sent an email each week to remind the nurse navigators about the study. When the nurse navigator had found a candidate the researcher was informed, and a reminder put in the booking system for the nurse who was caring for the patient in the clinic to introduce the study and deliver the letter of introduction to the patient. At first this was supposed to be done during an educational interview with the nurse before chemotherapy started. It was soon evident that would not work because the nurses found that the patients were being overloaded with information. They felt that it was too much to introduce the study at that time. It was therefore decided to introduce the study the first time the patient came in for chemotherapy. As in the study of Johnston, Pringle, and Buchanan (2015), feedback from the nurses was essential for the recruitment of participants. The patients were given a few days to consider whether they wanted to participate. The head nurse took the responsibility for asking the patients if they were willing to participate in the study. They were asked the next time they came in for treatment or by telephone. If they agreed to participate they signed a written consent. In the written consent the patients agreed to answer questionnaires on three separate occasions, give the researcher permission to view their electronic medical record, and being asked to participate in the research interview.

At the end of the second session with the support service the patients who had given consent to participate in the study were asked whether they were willing to be interviewed about their experience of opening a discussion on future care and being given the booklet. The researcher contacted the participants by phone within a week, explained the purpose of the interview and set a time for the interview that suited the participant and his family member. The researcher was able to interview seven patients of the 12 who agreed to participate. One patient was too sick to get the support service. Two patients were able to come have one session and then they died. One patient did not want a second session. One patient had two sessions with the support service and the discussion on ACP was opened and he got the booklet, but when the research interview was going to take place the patient had been admitted to hospital. He died in his home, where he wanted, two weeks later. Of the seven participants that were interviewed, six were female. Their ages ranged from 54 to 85. Four were married, two divorced and one widowed. Five of the participants chose to have one or more family members present. The period from the diagnosis of lung cancer until the ACP discussion was opened ranged from 3-5 months. The interviews lasted 32-66 minutes. All except one participant were receiving palliative chemotherapy for their lung cancer. Most of the participants had not discussed ACP before. None of the participants had limitation on life-prolonging interventions written in their electronic medical record when they first met the nurse in the HPCT.

## 2.7 Data collection

The patients and a family member were asked to engage in a semi-structured interview with the researcher where their experience in discussing ACP and using the booklet were to be discussed. At the end of the second session with the support service the nurse asked the patients for permission for the researcher to contact them to set a time for a research interview about their experience of opening the ACP discussion. In most cases the researcher had also had the ACP discussion with the patient. It was decided to have the research interview after the second session due to concern about the patients not being well enough to attend the third session or because they might have been discharged to the home palliative care service because of the severity of their symptoms. Hence, the key focus of this study was the experience of patients and their family members of having the ACP discussion opened in the second session. The researcher contacted the participants by phone within a week, explained the purpose of the interview, and set a time for the interview that suited the participant and his family member. The interview took place at the patient's home or any place the patient found convenient and the patient was asked to have a family member present at the interview if that was possible. The participant's home was chosen as the preferred place to conduct the interview because it would be comfortable and private for the participants and their family members (King & Horrocks, 2010). An interview guide was used to structure the interview (appendix 3). The interview started with an introduction from the researcher on the purpose of the interview and, how the data would be treated, and permission was sought to audio-record the interview. Then the researcher asked an open and broad question and if the answer did not give much information then the researcher probed more into the subject by using other questions in the schedule (see interview schedule). The main question was: *Could you please, describe for me your experience of discussing advance care planning and your thoughts on using the booklet to do that?* Probing questions were for example: *Did you discuss this with your family after you got home, did you write in the booklet? What was the most difficult thing in having this discussion? What was helpful?*

Permission was gained to audio-record the interviews, which were then transcribed verbatim where the voice of each participant was recognized. Silence, tone of voice, laughter and gestures were noted as well as possible by the researcher in the transcription. The transcription was carried out shortly after each interview. This was done to contemplate how each interview had gone, to see whether the information sought was retrieved, and to subsequently fine tune the interview guide, if needed. It was also important to take into consideration that the research subject was delicate and maybe there might have been a need to adjust the questions. For example, if any question were to elicit a strong emotional reaction it would have been necessary to make changes to the interview guide. It was also practical to type each interview immediately to distribute the workload.

After each interview the researcher wrote down her reflections on the interview in field notes where she wrote what she saw regarding the reactions of the participants and how she herself was feeling during the interview. The field notes were descriptive and contained a subjective description of the reaction the patient and his family member showed in the interview. This description included for example how they touched each other, non-verbal expressions, tears and tone of voice. The researcher asked herself how she could tell how they were feeling. The field notes also contained a

description of how the researcher was feeling during the interview, and also why she was feeling that way.

Field notes were also written in the same way after each ACP discussion in the support service provided by the palliative care nurses. These notes focused on the feelings and perceptions of the palliative care nurses related to how the patients and family members seemed to be experiencing the discussion and the nurses' perceived acceptability of having the discussion based on their feelings and thought processes during the discussions.

## **2.8 Data analysis**

The interviews were analysed into themes using thematic analysis. Thematic analysis is a qualitative research method and is used to create a systematic framework to code qualitative data. The coding is then used to create patterns across the data to answer the research questions (Braun & Clarke, 2014). In this study, thematic analysis was used as a way to search for certain themes or patterns across the data set to provide a way to answer the research question. Before the researcher started to work on the data analysis she wrote down questions that she thought would aid the analytical process. This included questions such as; what is the participants' experience of opening the ACP discussion in this way? And more specifically, is it timely? What is their experience of using the booklet? Is there anything that is particularly difficult about the discussion?

The thematic analysis was done in six phases in accordance with Braun and Clarke (2006). The first phase was to familiarize the researcher with the data at hand. The researcher in this study was taking the interviews and transcribing them herself so she knew the data beforehand. She read the data entirely once before she started searching for meanings and patterns and began coding the data. During multiple readings the researcher emerged into the data by reading it in an active way. During the readings the researcher took notes and marked ideas for coding.

The second phase began when the researcher had familiarized herself with the data and had made a list of ideas that were interesting. She then identified codes that appeared interesting and helpful to answer the research questions. Coding is a systematic way of organizing and finding meaningful parts of data that relate to the research questions. These codes are narrower than the themes that are interpreted by the researcher out of the data. The data was approached with certain questions in mind that the researcher was planning to code around. The coding was done manually by writing notes in the transcripts and by using highlighters to indicate patterns. The parts of data extracts that fitted together in each code that was found were copied and pasted into a separate file, putting them together under each code in a spread sheet. The coding was done to reduce the data and simplify it, to make it more manageable. At the same time the coding can make the data more complicated by creating more questions and new interpretations.

The third phase started when all the data had been coded and a spreadsheet had been created with long lists of different codes. Then the researcher started to search for themes within the codes. This involved sorting the different codes into potential themes and considering how different codes might be combined to form a theme. This phase ended by collecting candidate themes and sub-themes and the codes that belonged to each theme.



The fourth phase was to review the themes by looking at them in detail to see if they held as they were or needed to be combined, separated, refined or even discarded. The researcher needed to see that the themes were meaningful and that there was a clear distinction between them. At that time the researcher reviewed all the coded data extracts that were coded under the theme and considered if the extracts really fitted with the theme and if they really made a coherent pattern. If they did not fit then the theme needed to be reworked. When the researcher was satisfied that the themes captured what the coded data entailed, the researcher went through a similar process with all the dataset. The researcher considered the validity of individual themes in relation to the data set and whether the meaning represented the data set as a whole. If the researcher was not satisfied that the thematic map worked, the researcher had to further review and refine her coding and maybe identify new themes. When the refinement did not reveal anything substantial and the researcher was satisfied that she had a thematic map of the data set she went on to the next phase.

In the fifth phase the researcher identified the essence of what each theme was about and determined what part of the data each theme captured. This was done by going back to the collated data extracts for each theme and organizing them into an account, then putting them into a narrative showing what was interesting about them and why. By the end of this phase the themes were clearly defined and the researcher began to think about names for the themes.

Phase six began when the themes had been worked out and the researcher started to write the final analysis and report of the findings of the study. The researcher told the story of the data in order to convince the reader that the themes she found were valid. The analysis had to provide sufficient evidence of the themes in the data by showing data extracts that captured the point the researcher was making about the themes. The co-researcher and supervisor of the master's thesis also read all the data and worked on the analysis with the researcher, and they reached an agreement on the themes. That was done to add to the credibility of the results. In addition to the thematic analysis, the reflective notes, written after each ACP discussion and after the interviews, added a secondary data source that validated the patients' and family members' experience (Krefting, 1991). These reflective notes were not analysed into themes but extracts from the notes are presented in the results to demonstrate the nurses' feelings during the ACP discussions. These extracts support the findings from the research interviews and support the findings that facilitating ACP for this patients group in this way is acceptable.

## **2.9 Validity**

Rigour in research is the way in which integrity and competence is demonstrated to show the legitimacy of the research process, and is important both in quantitative and qualitative research (Tobin & Begley, 2004). Another word for rigour in qualitative research is trustworthiness (Krefting, 1991). Credibility of research is about the aim of the study and it refers to how well the data and the analysis of the data address the intended objective of the study (Graneheim & Lundman, 2004). The researcher believes that the methods chosen to obtain and analyse data, add to the credibility of the results. The data collection must contain descriptions and perspectives from different participants on the experience studied (Graneheim & Lundman, 2004). In this study the participants were different as

regards age, sex, geographical area, marital status and life experience. Validity can also be increased when the data analysis is performed by more than one researcher (Mays & Pope, 1995; Polit & Beck, 2012). In this study the thematic analysis was confirmed by the supervisor, Erna Haraldsdottir, who read the transcribed data that formed the themes. She is a skilled and experienced researcher in qualitative research. Writing reflective field notes after each meeting and the research interview was done to make transparent the researcher's understanding of the experience. This could serve to enhance the credibility of the study (Krefting, 1991; Mulhall, 2003). Several methods can be used to increase rigour and validity in qualitative research and most of them refer to the trustworthiness of the research (Polit & Beck, 2012). Providing clarity and transparency about the research methods increases the trustworthiness of the research ((Cutcliffe & McKenna, 1999; Jonsdottir, 2012; Yin, 2016). The researcher describes in detail how the data collection and analysis were done. By being faithful to the participants, honest and precise in analysing the data and following the methods that the researcher chose for the study she is also increasing the trustworthiness of the study (Jonsdottir, 2012). The results of qualitative research cannot be transferred to other patients; however, the findings can provide insight and enhance understanding of the experience and can give an indication that other patients in a similar situation might have similar experiences (Polit & Beck, 2012; Yin, 2016). In the end it is for the reader to decide whether the findings can be transferred to other settings (Graneheim & Lundman, 2004; Krefting, 1991). The researcher tried to use detailed transcription techniques where silences were also put into the transcription as well as other non-verbal communication when possible. That was also done to add to the reliability of the analysis (Seale & Silverman, 1997).

## **2.10 Issues to consider in research in palliative care**

There are many issues to consider when conducting research. Many things can influence how studies are carried out and they have to be taken into account. One of these issues is role confusion, when the HCP who provides the intervention is also the researcher (Johnston et al., 2015). In this study the nurse who provided the support service also conducted the research interview. This can be both an advantage and a disadvantage. The participant did not know until the end of the second meeting when he was asked to participate in a research interview that the nurse in the HPCT was the researcher. In the research interview, the researcher tried to be very clear on the purpose of the interview. This might lead the participant to be reluctant to provide negative feedback on the intervention because the researcher is part of it. However doing research in this population the researcher needs to be sensitive to the patient's wellbeing and respect their perspective, for example, sometimes patients do not want to know that they are dying (Johnston et al., 2015), so the researcher needs to be careful in conveying information to the participants. Knowing the patient can be helpful in this situation. It is also a difficult time in the life of the patient and the family member, being diagnosed with advanced cancer.

There is also a need to recognize emotions felt by HCPs involved (Johnston et al., 2015), like in this study the emotions of the nurses who introduced the study. Some of the nurses had the perspective that palliative care equals end of life care and might therefore have been hesitant to introduce both the support service and the study the HPCT was doing. In this study the researcher had the advantage of knowing the environment the study was conducted in, knowing the nurses that would be introducing the study, and having provided care to the patient group for quite some time.

It can be challenging to do research in the palliative care population. One of the challenges can be reluctance to approach patients who have been diagnosed with a serious illness and ask them to take time and effort to participate in research. However, there is an indication that patients are favourable to taking part in research even when they are at the end of life (Johnston et al., 2015). The majority of patients who were asked to participate in this study were willing to do so even though a few patients suggested to the head nurse that there was no point in them taking part because they were at the end of their lives. There is also the issue of HCPs wanting to protect patients from taking part in research because of their advanced disease (Johnston et al., 2015). Therefore, there needs to be trust between the researcher and the HCPs who recruit participants and introduce the research to patients. It is important to understand the experiences of patients that have serious illness and are at the end of life. When the research is sensitively conducted, it can be done in the palliative population (Johnson et al., 2015).

## **2.11 Ethical issues**

Ethical approval for the study was obtained through the ethics committee of Landspítali (appendix 4) and from the chief medical officer at Landspítali (appendix 5). The study was reported to the Data Protection Authority in Iceland. The nurses in the outpatient clinic introduced the study and delivered a letter of introduction (appendix 6) to the patients during their first chemotherapy session. In the next session the patients had in the clinic the head nurse asked them if they would like to participate, after being given time to think it over. If the patients agreed, they signed a written consent (appendix 7). The participants were able to withdraw from the study at any time without impacting their treatment or their relationship with their clinical team.

At the beginning of the research interview the researcher explained that the data from the interviews would be used to answer the research questions but what was said in the interviews would be documented in such a way that it would not be possible for others to know who had said what, even though what was said was quoted. Hence, anonymity would be ensured in the transcription of the interviews and all publications.

Part of the support service involves discussing delicate matters that can be hard both for patients and their family members. Hence, the researcher has vast experience in this field and was well placed to conduct the interviews in a sensitive way. The researcher was well aware that during the interviews, difficult matters would be discussed and she was able to address these issues with great care, and asked the patient and their family members for permission to discuss difficult matters. The topic of the research interview can be demanding for participants and their family members and in the event that the researcher felt that they were feeling distressed about what was being talked about, the researcher would offer support from a hospital chaplain who was working at the Palliative Care Unit (appendix 8).



### 3 Results

This study explored the patient's and family member's experience of opening a discussion on ACP as a part of the support service provided by nurses in the HPCT to patients with advanced lung cancer. The results indicate that the participants and their family members found it both acceptable and helpful to open a discussion on ACP. The patients wanted to protect their family but also to prepare their family for their death. The patients felt that the discussion was relevant and helpful, especially for their family, but uncomfortable. The timing of opening the discussion seemed to be right for the patients and their family members present in the interviews. The patients had thought about issues that were addressed in the booklet but had not discussed these issues with anyone. The booklet was found helpful for the discussion, even though the patients had not written anything in it. The framework for the support service and the booklet supported the nurses in opening the discussion and made it easier than they had anticipated. This chapter demonstrates key themes that reflect these findings.

#### 3.1 Wanting to prepare and protect the family

It was evident that the ACP discussion was seen as helpful by the participants as this would prepare the family for the future, but at the same time they wanted to avoid discussing what was ahead and plans for the future. For example one participant felt that discussing ACP with the children would only worry them and in that sense not be good for them.

Participant 3 (P3): I'm not going to burden them with it so they need to be on their toes.

The protection of children was also evident in what another participant said, who thought that seeing the booklet had perhaps caused the son to get upset. This participant talked about not having discussed these matters with the children in spite of having made financial arrangements.

P4: But we have not discussed these matters. I saw that my son became a little bit startled when he saw this booklet.

The need for protection of the family was also evident when a family member felt that discussing ACP with other family members might be untimely. Here a family member tells the researcher that the participant had asked if he should give the booklet to his parents and the family member wanted to wait.

Family member 1 (FM 1): She asked me whether she should take the booklet to our parents who live next door and let them read it. I thought (silence), oh my God, let's wait a bit.

However despite wanting to protect the family from the ACP discussion it was also evident that both the participants and their family members felt that the main reason for having this discussion was the benefit for the family. As these three participants said:

FM 1: There is one thing that we do know, that if you can lighten the burden for your family by telling them your wishes about whatever it is before death or when you are too

sick to tell them, it must help the people who are taking care of that person. That is why I think it is very good to open the discussion.

P4: I think that it is very clever to have such a booklet, I think it like, lightens the burden. You see, here you have good questions, that cover a lot, especially for the family.

P6: It is of course good for the family that it [the booklet] exists.

Financial arrangements were one of the main elements that were important to the participants to prepare their family for their death. Two of the participants had already gone into their finance after they were diagnosed with lung cancer and made financial arrangements so everything would be ready for their children at the time of their death. But they had not discussed this further with their family members.

P4: In connection with finance, I was really, I had started to think about it a lot, what are my children inheriting, started to think about that and look into these matters and checked it all out. My private pension savings and all that, and I finished that. It's all in a certain book, I have told them about that.

FM7: She [the patient] was also taking care that we would not have to handle something that would be difficult for us when she passes away, like she has already put money aside for the funeral.

There was also an element of protection from the family members themselves not wanting to discuss issues of ACP with the patient, as they wanted to avoid the discussion in order to remain positive. For example one of the participants had been trying to get the spouse to talk about these matters but felt that the spouse was not willing to talk about it and that the spouse wanted to stay positive and believe that everything would be all right and not face the fact that the participant would probably die of lung cancer. The following is a quote from the participant who did not have a family member present in the research interview.

P5: You see, this is not something that is discussed. My husband does not talk about this...so you can see that it is really difficult to talk about things when you don't want to talk about the negatives. And if you have the opportunity to push it aside, I think it is tempting to do that.

However, it was evident that this participant felt that it would be very beneficial for the spouse if they were able to have a discussion on ACP. The participant's main concern was not about what would happen to him, rather what would become of the spouse and the participant's father after his death. This quote is from the same interview where the participant did not have a family member present and he is telling the researcher how the conversation had gone when he tried to open a discussion on future matters.

P5: I told him on our way there, I said to him: Dear [spouse] we need to discuss this, I mean he is ten years older than me, we have always assumed that it would be me that would outlive him because I'm much younger. ...Then I would have to take care of his

matters if anything were to happen to him, but we haven't discussed it the other way round. And we need to designate someone to take care of your affairs if anything happens. This is the first thing he has been willing to discuss.

P5: And here is something I haven't yet been able to foresee and it bothers me a bit, my father is 85 years old and he has always depended on me.... I mean, it is really difficult and it was really hard at the beginning to think about what will happen to him.

The patients and their family members did not show strong emotional responses to the ACP discussion, they seemed to be quite calm and prepared to engage in the conversation and the strongest emotional response they showed were tears and a broken voice. The tears seemed to be mostly when they were talking about their family, which seemed to be their primary concern. This was reflected several times in the field notes, like:

She seems to be balanced when she talks about this but when she talks about her children, there are tears in her eyes.

### **3.2 Acceptable to open up the ACP discussion but not yet ready to take it further**

All the participants accepted the nurse's offer to open up a discussion on the future. They said that it seemed natural when it was brought up in the support service and even felt that it came so naturally that it could not have been planned as such.

P4: I was wondering when you are seeing people several times whether you are always ready with the booklet when an opportunity arises. At least I thought that it really fitted well into the discussion, into what we were discussing. Yes, you seized the opportunity.

Some of the participants felt that ACP should be a discussion that all people should have at one time or another.

P1: I would give the booklet a ten, this is such a needed discussion and not necessarily just for those receiving palliative care, you never know when your time is up, to have something like this in a good place and having discussed these matters and made some decisions. I think that is positive for everyone, I think so.

It was evident that some of the participants and their family members felt that having the discussion early was beneficial. One participant thought the discussion should be opened early because then the patient would not be too sick to have it.

P2: I think that it helps a lot, just in itself, of course you need to think about it, it is of course better to look into these matters, think about it while you have the endurance to do it, that is just the way it is.

While the participants and their family members felt that it was helpful to open the discussion it was evident that writing in the booklet was not easy and only one of the participants had done so before being interviewed. They talked about reading the booklet and thinking that they would probably write in

it someday. One participant talked about needing time to understand the situation before being able to talk about it.

P5: Yes it is of course, of course you need time to get to the point that you are willing to discuss this. Yes, it is a process and you know, being prepared to really discuss that maybe I won't be here at Christmas.

It was noticeable that having an ACP discussion was not something people were used to. Some of the family members felt that it was good to open up the discussion because this was not something that was usually discussed. Two family members said:

FM6: Yes just here, this is not something you bring into the conversation just like that (laughs).

FM4: I feel that it is good to know what she wants, this is not a subject that you just start to discuss.

One family member felt that it was good that the discussion was started and to be given an opportunity to discuss things they normally would not discuss.

FM6: I really liked it and I appreciate coming into an environment where limitations to treatment are discussed and I don't need to broach the subject and I have no responsibility for how it is documented in the system because you feel that you are in an uncertain position when you are not receiving treatment for your disease and don't have a certain physician. I felt that it was a great way to open the discussion. I also feel that this is a good enterprise because in it are things, yes that I had not thought that mattered, I have heard that some people want to organize their funeral and that they want to stay in the hospital and these things, but then there are other things in the booklet that I have never thought about. I think that is a good thing.

It was evident that most of the participants were not ready to write in the booklet and had not taken the time to think about these matters and decide how they wanted things. One participant said:

P1: I don't know, I feel that I am not quite ready to answer all this. Like for example this, the funeral arrangements.

When asked about the timing of opening the discussion one participant said that he felt he was not ready to discuss this with his family because he did not feel sick and that it felt so unreal that he had lung cancer. After having said that, he suggested to his spouse that he could talk about these matters with their children.

P3: I won't know until I start experiencing severe symptoms, like I have been saying, I haven't realized this [having lung cancer] yet. But maybe you [speaking to spouse] could speak to them about this.



### 3.3 Relevant, helpful and timely opening of ACP discussion

It is noticeable that while the patients and their family members felt that the ACP discussion was relevant and helpful and the timing appropriate, some of them also said that these matters could be uncomfortable to discuss. This is reflected in the following quote from a family member:

FM1: you know it definitely helps to discuss these matters, not to close the subject and think nothing is going to happen to me. I find these matters uncomfortable to discuss, but it is just something you know, that we are all going to die someday.

The timing of opening the discussion, shortly after having been diagnosed with advanced lung cancer, seemed appropriate. None of the participants felt that the discussion had been opened too early but they admitted to being a little bit startled by it. As one participant put it:

P3: I was a little bit startled, but yet not, well but not. I just did not realize that I was sick (silence).

One family member thought that patients would not think of these matters until they were in a panic, realizing that they were dying. Therefore, they felt that the booklet would help patients to think about these matters earlier.

FM1: you know, I think that people don't think about this except in a panic when they see where things are headed, when the end is approaching...yes, I remember very well the young couple who were in a car crash three years ago. She died immediately but he lived for a short time and he had talked about donating his organs.

It was evident that being referred to a palliative care support service was for some an indicator of the seriousness of the situation. Two of the participants reported that compared to the opening of the ACP discussion they were more startled when the support service was first introduced to them and they were told that it was provided by the HPCT. One participant said that the timing of opening the discussion was all right:

P5: I thought that it was okay [opening the discussion], but it was different when the palliative care team was discussed [when the support service was introduced].

One family member said that he had started wondering if the HCPs knew something that the patient and the family member had not been told when the support service was introduced.

FM1: I thought (the voice breaks) (silence) at first when she had the first interview in December when they talked about the palliative care team... then I felt a tightness, palliation, is that death? You know...and then came another question to my mind, do they know something more than we know?

Some of the participants and family members said that the booklet and discussion got them to think about ACP. One family member said this and thought that some people would react differently to the discussion:

FM2: That gets people to think, that it is good to, you know. But I can imagine that some people could take it differently...just, you know, like I am saying, people just face the situation, or the other way round but I think that they just, as I say, they face things as they are.

And another family member said this about the timing:

FM3: I think that is the appropriate time to open the discussion. I mean, we know that he has a serious disease and that everything is being done so that he can still enjoy the time he has left.

Because the subject of death and dying was uncomfortable the participants seemed to be very hesitant in opening the discussion with their family both to protect themselves and their family. One participant wondered if people were ever ready to discuss these matters, and hoping that they would live longer.

P3: Well, are you ever ready? (silence) I hope that I will live a little bit longer, hopefully some time but of course you never know.

### **3.4 Having thought about it but not discussed it with anyone**

It was evident that the participants had thought about ACP issues but most of them had not discussed them with anyone. One participant said that he had been thinking about these matters since he was diagnosed but had put it to the back of his mind because it was so difficult to think about.

P1: I know that this is somewhere here inside (points to her head), this thought and these thoughts but I have always since I was diagnosed pushed them ahead of me, pushed them aside. I don't know whether I'm ready to face this (silence) or whether I feel that it is uncomfortable, I don't know.

It was evident that many of the participants had already thought about the issues in the booklet and had formed an opinion on how they would like to have things for themselves but had not informed their family members or HCPs. Many of the participants mentioned not wanting cardiopulmonary resuscitation. One put it like this:

P2: Nothing but, I do not want to be resuscitated or something like that, those are things that...I haven't discussed this with anybody but if I am too sick then I don't see the point.

And another said this:

P3: For example I am not in favour of resuscitation if it is only to keep you breathing and therefore I would not want that.

The participants seemed to know that their disease was incurable and they hoped to get as much time as possible and tried to live a normal life. This is reflected in the field notes. Here are two quotes from the field notes:

The patient tells me that the disease is incurable and that he is hoping for more time. He was determined from the start to accept the treatment that was offered to him and everything else that was offered.

The patient and his family member realize that the disease is incurable and will cause death for the patient.

Two of the participants discussed where they would like to be cared for at the end of life, two talked about the decision to be cremated and one had made arrangements for his funeral. Many of the participants had thought about the issues in the booklet, but not discussed them with anyone and seemed to welcome the opportunity to inform both their family member and the HCP of their wishes.

### **3.5 Booklet helpful to open up the ACP discussion**

The participants found the booklet helpful in many ways. Two of the participants laid the booklet out where it could be seen by family members to open up the discussion. One felt that it was good to be able to write in the booklet to share what he wanted instead of having to tell his family members.

P4: I feel that it is really convenient, instead of having to discuss and ask, and not only about things connected to the funeral, but also wishes you have like what your want concerning resuscitation and such things, you know.

One participant had been having trouble communicating with his spouse and children about his illness and cried when he talked about wanting to hand the booklet to his family members to read with him to try to start the discussion.

P1: I would have wanted my family at home to read it (with crying in his voice). I would want (silence) just to hold it and say I would like us to read this together, yes.

Many of the participants and family members thought the booklet, as a whole was helpful, because it asked many relevant questions that some people had not really thought about. One participant described the booklet this way:

P4: but I think that it is very clever to have such a booklet, I think it like, lightens the burden. You see, here you have good questions that cover a lot, especially for the family.

And a family member said:

FM1: I just felt that the whole thing was helpful, because it hadn't crossed my mind, you know like the important affairs checklist, something like doing all these things, someone knows all these things and can manage everything.

### **3.6 Evidence from reflective notes – ACP discussion – easier than anticipated**

The reflective field notes provide additional data on how the two nurses who facilitated the ACP discussion felt about opening the discussion at this point in time using the framework for the support service and the booklet. It is important to know how nurses feel in the role of facilitating ACP discussions as this provides information as to how this sits within the role and competence of a

palliative care nurse. What became evident in the field notes was that facilitating the ACP discussion felt easier than expected. It was perceived by the nurses that they felt that it gave them comfort to have the framework for the support service that introduces the purpose of the discussion and validates that having this discussion is something that is always done and is not because there is a change in the patient's condition. Using the booklet also seemed to be helpful in opening the discussion and introducing the subject of the discussion. In spite of the fact that in some of the interviews the opening of the discussion was not a natural continuation of what was being discussed previously, the nurses felt that it was right to open the discussion. All the patients and their family members said yes when offered the chance to talk about the future and showed interest in the booklet and took it with them. None of the participants expressed openly strong or uncomfortable reactions when the nurses opened this discussion and these matters were discussed. In this example from the field notes the nurse is reflecting on an interview where the discussion was opened with a patient and a daughter:

After the symptom assessment I open the discussion on the future and get permission to talk about treatment in the future and introduce the booklet. They [the patient and daughter] welcome the discussion and seem to find it normal to bring it up. They tell me they have already discussed funeral arrangements and have already organized that. They would like to know what is in the booklet. I go over each section of the booklet. They speak very frankly about death and dying. They find the uncertainty hard. They ask about prognosis, I ask them if they would like to know more and they tell me that they do. I tell them that I think that she has probably months rather than years to live. They ask if I think she will survive to see a new year. I tell them that I would be surprised if she did. They seem to find it beneficial to get the information and she tells me that she will then have to hurry to do things she wants to do...They think that her husband is having the most difficult time now because he will not accept that she is dying from this disease within a short period of time. He has not been willing to discuss this...I cannot see that they show any particularly strong emotional reaction. I felt good during the interview, I felt that they were ready for the discussion and it was not hard to open the discussion.

Here the nurse reflects on an interview where the discussion was opened with a patient and a spouse. It was not as natural to open the discussion with this patient because it was not a logical continuation of what had been discussed previously in the interview.

I tell her [the patient] that it is a part of the support service to discuss what is ahead and ask if she is interested in talking about the future. She accepts that. I tell her about the booklet and go through it page by page. She tells me that she thought about these matters just this morning when she wasn't feeling so good and says that she wants to discuss this and prepare even though she cannot comprehend that she will die within a short period of time. She and her husband seem to be in tune with the conversation, discuss every section of the booklet, and seem to find that every section is relevant and ask questions. They seem to welcome the discussion. The patient tells me that her husband probably doesn't know that she is thinking about these matters and that they

haven't discussed it. The husband says that he understands that she has a need to discuss these matters. She accepts the booklet but tells me that she is not ready to write anything in it yet or discuss it in the next few days...I was ambivalent on whether I should open this discussion with them. I did not think it was a logical continuation of the conversation we were having but when I had introduced the aim of the discussion and saw how they welcomed it I felt relieved. They did not seem to find it uncomfortable. It will be interesting to find out in the research interview.

Here the nurse is reflecting on an interview where she opened the discussion of ACP with a patient and a daughter:

I tell them that it is a part of the support service to discuss the future to prepare in case things turn out for the worst. The patient then asks whether I expect that something is about to happen and whether it will happen quickly. I tell them that we choose to discuss these matters when everything is calm and the reason why I have opened this discussion is not that I think that things are about to change. I get their permission to introduce the booklet, hand it over to them, and go over each section. The patient tells me that in their family they talk things over in an honest way and they have already discussed some of these issues. For example they have discussed that she wants to be cremated. The daughter has tears in her eyes at this point in the conversation. The patient is on the other hand smiling and seems to be quite comfortable discussing these matters. They tell me that they are pleased to have received the booklet and plan to look at it at home. The daughter gets a copy for herself. I discuss with them what we discussed in the last interview about her not wanting cardiopulmonary resuscitation and that I have documented that in the electronic medical record...I felt good during the interview. I felt that opening the discussion went well even though it was not a continuation of what was being discussed but connected to what was discussed in the first interview.



## 4 Discussion

The focus of this study was to explore patients' and family members' experience of engaging in an ACP discussion facilitated by palliative care nurses as part of a palliative care support service for patients newly diagnosed with advanced lung cancer. The main focus was on the opening of this discussion early, or shortly after diagnosis of advanced lung cancer with the aid of an ACP booklet, and whether this was seen as acceptable from the patients' and family members' perspective. Facilitating the ACP discussion consisted of the patients being asked permission to start a discussion on future care near the end of the second session with a palliative care nurse. After gaining permission the palliative care nurse introduced the contents of the booklet. In the booklet there are questions raised about the patient's values and goals concerning future care, preferences for end of life care and funeral arrangements. The patient and family member were given an opportunity to discuss these issues, ask questions and take the booklet with them home. In this chapter the researcher discusses the key findings of the study and how they relate to the wider literature in relation to when ACP discussion should happen and in what context.

The key results of this study demonstrate that the participants found it acceptable and appropriate to open the discussion on advance care planning in the proposed way and at this time. These are important results as it is not clear in the literature when ACP discussions should take place in practical terms, but it is suggested that the discussion might best be initiated following diagnosis of a life-threatening disease, when there is a shift in the focus of treatment, when individual needs are being assessed, when there are repeated hospital admissions (Henry & Seymour, 2008), or after the disease had recurred (Barnes et al, 2007). Guidelines propose that discussing ACP is a process that should be initiated after the patient has been diagnosed with a serious illness (Henry & Seymour, 2008; NCCN, 2014). The results of this study indicate that the timing that was decided for the ACP discussion to be introduced was appropriate. The condition of two patients in the study deteriorated quickly and they died before their second session in the support service, one was too sick to attend the first session and one died briefly after the second session. Therefore it can be argued that it is sensible to open the ACP discussion early in the disease trajectory with this patients group. A crucial component of opening the discussion is getting permission so that the patient has an opportunity to opt out of the discussion when not ready for it. In the framework for the support service it is an important component to give the patient the opportunity to reject the opening of the discussion.

By facilitating the discussion in a routine way rather than waiting for a specific moment seemed to 'normalise' the discussion. This is in line with guidelines that propose that ACP discussions should happen early and HCPs should not wait until crisis situations arise (Henry & Seymour, 2008). The palliative care nurses who facilitated the ACP discussion felt that the framework they used and the booklet were helpful and supportive in opening the ACP discussion and it was easier than they anticipated. It has been stated that one of the barriers to discussing ACP are time constraints (Ke et al., 2015; Lund et al., 2015). Opening the ACP discussion in this study was done at the end of the second session with the support service and probably took under ten minutes. The initiation of the discussion gave the patient an opportunity to raise the issue with the family and HCPs, and the patient

could use the booklet as a tool to continue the discussion with the family. It also gave the patient and family a signal that ACP was something that could be discussed with HCPs in the future. After opening the discussion it is in the hands of the patient how to proceed with the discussion. The palliative care nurse then continues to give the patients opportunities to continue the discussion.

It was evident that the patients in the study wanted to protect their family and therefore they were often reluctant to discuss matters of ACP with their family members. Yet they believed it would be helpful for their family members to know what their wishes were for end of life and they wanted to prepare them for their death. In a similar study the family was the main factor that influenced patients to plan the future, but at the same time they were worried about upsetting the family by making plans (Horne et al., 2012). These results are in harmony with results of several studies (Johnson et al., 2015), that show that the family can both be a motivator and a barrier to ACP, because patients feel that the discussion can upset the family, and at the same time patients feel that it can ease the burden for the family. A study by Simon et al. (2008) also showed that the patients felt comfortable that they had reduced family stress after going through a process involving ACP. It is important to encourage patients to have family members present during ACP discussions. It was evident in this study, that when family members were present as the palliative care nurse opened the discussion, it helped the patients to continue to discuss ACP with their family members. Thereby the nurse could help both the patient and family to have this discussion. The nurse gave the message that ACP is something that is important to discuss, and better to do it sooner rather than later. Numerous studies confirm that most patients with cancer take part in ACP to do what is in the best interest of the family (Johnson et al., 2015). Studies also reveal that patients feel that taking part in a discussion on ACP is an experience that they would like to share with the family (Johnson et al., 2015).

Even though the patients in this study found having the ACP discussion acceptable and helpful in the way it was done and at that time, most of the patients found ACP issues difficult to discuss. This difficulty was reflected in that most of the patients were ready to engage in the discussion but said that they were not yet ready to take the discussion further at this time, but said that they would do it later. This study confirms findings from other studies, highlighting the sensitivity that needs to be around ACP discussions (Barnes et al., 2012) and that ACP is a process that can be initiated by HCPs (Lorenz et al., 2007), but should be progressed with patients and their families with the pace they choose. In this study it was evident that starting to have the discussion with a palliative care nurse enabled the patients and family to begin the ACP discussion. By opening the discussion with the nurse, the patient and the family had perhaps taken the first difficult step and could then control themselves what would happen next. The research interviews were conducted one to two weeks after opening the ACP discussion. Maybe if the research interviews had been conducted later the results might have been different, and more patients would have written in the booklet and discussed ACP with their family. ACP is a process and takes time. Opening the discussion is only one of the first steps in the process of facilitating ACP, and is the main focus of this study. Many of the participants told the researcher that they would write in the booklet later and were planning to talk with their family about these issues. Some of the participants felt that they were not ready to write in the booklet because they did not feel sick or they had not yet realized what the diagnosis of lung cancer really meant for



them. This is similar to the results from another study on lung cancer patients (Horne et al., 2012) mentioned previously, where many of the patients did not feel ill and therefore did not see the need to discuss the future. Rather they felt that it was a hard thing to talk about and wanted to put these thoughts aside. It is well possible since the process seems to be hard that palliative care nurses have a vital role in facilitating the process in a sensitive manner, opening the discussion early, shortly after the time of diagnosis. This study indicates that when done in this way, it is appropriate for the ACP discussion to be part of a palliative care team support service.

Evidently many of the patients in the study had thought about ACP but had not discussed it with anyone. It is one thing to think about ACP, another thing to discuss it. Other studies highlighted that patients have often thought about these matters but do not want to initiate the discussion with family members or HCPs and they want the HCPs to start the conversation (Simon, Porterfield, Raffin Bouchal, & Heyland, 2013). Patients and families have the expectation that the HCP knows when it is time to initiate this discussion (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011). This study supports these findings and demonstrates that it is appropriate for palliative care nurses to take the initiative of facilitating the ACP discussion. By opening the discussion the nurses are creating the opportunity for patients to discuss ACP with their family and from that take the lead on how ACP will progress from there. There was also evidence that the booklet supported opening the discussion, it became a 'tool' that was used to aid the discussion, for example, some of the patients would lay the booklet on the table for family members to see or hand it to family members to read. Evidently, for the patients in the study, the main objective of the booklet was not to write in it, but it became a way of opening the discussion between the patient and family members.

Facilitating advance care planning is a process. Opening the discussion is just the beginning of that process. There is a need to develop this process further to find out how best to progress with the discussion and find out what patient's wishes are related to end of life care and how that can be achieved. It is evident that there is a need to continue the ACP discussion with the patients. Optimally it should take place during several sessions (Barnes et al., 2012) where the patient and his family member get opportunities to discuss their goals for treatment, get information about prognosis and treatment options, state their wishes and review what they have decided on previously.

Research has highlighted that conversations on ACP are conducted in a timelier manner when patients receive care from palliative care services (Stevens & Whyte, 2011). It may be speculated whether palliative care HCPs have permission from patients and family to talk about these issues because of what they represent. This study highlights that palliative care nurses are well suited to facilitate ACP using their communication skills and by drawing on their experience and training they have to conduct these conversations. The question then arises whether other nurses providing care for patients with advanced disease could open the discussion on ACP in this manner. A synthesis of the literature demonstrated that nurses perceive that they are in a good position to facilitate ACP discussions (Ke et al., 2015). Nurses are often the HCPs that are closest to patients and their family members and therefore often have knowledge about patient's wishes. Most of the reviewed articles (Ke et al., 2015) showed that nurses have several roles in the ACP process. Nurses should assess patients' needs and preparedness for the ACP discussion and help patients to think and talk about

difficult matters. However, it is evident that nurses need education and training to be better able to take on the role of facilitating ACP (Ke et al., 2015).

The literature indicates that nurses are well placed to facilitate ACP discussions (Ke et al., 2015; Sulmasy et al., 2008) and this should be part of palliative care services (NCCN, 2014). However, there is limited literature that demonstrates in practical terms how this can be done in a sensitive and person-centred way. The results of this study demonstrate that opening the ACP discussion after a palliative care nurse had met the patients once, was seen as acceptable by patients and their family. Hence, incorporating the ACP discussion as part of the support service was seen as appropriate and acceptable by patients and families. It is part of palliative care to discuss ACP and the palliative care nurses in this study were in a good position to facilitate a discussion on ACP having the experience and training to do it. They felt that the opening of the ACP discussion was easier than they expected even though in some of the interviews they found that this was a complete change of subject. Just explaining that it is something that is always discussed in the support service, not because something is changing in the patient's condition and normalizing the discussion helped the nurses initiate the discussion. They also found the booklet helpful to have the discussion. It was interesting that the participants in this study also found the booklet helpful to open the discussion with their family. It was really surprising to the nurses how well the patients and their family members responded to the opening of the ACP discussion considering how delicate the subject is.

This study explored the experience of a small purposive sample of patients with advanced lung cancer. Results give an indication that it is acceptable to open the discussion on ACP in the proposed way. Findings cannot be generalized to other patients due to the nature of the study design. Another limitation was time constraints limiting the number of participants and time for follow up. Only one male participant took part in the study. Having the interview after the third session with the support service would probably have deepened the results. It would also have been very valuable to interview the family after the patient's death. It could have given a more overall view on the process of ACP and perhaps more knowledge on the impact of the intervention. Forty percent of patients invited to participate in the study declined and these patients could have had a different experience. The palliative care population is a delicate group to study. There is always the possibility of the patients being too ill to participate, as was the case in this study. Finally, the researcher was one of the two nurses providing the intervention being studied. Therefore the participants might have been influenced to provide the researcher with a more positive perspective of the intervention. Concurrently, this also strengthened the study where the researcher was familiar with the patient group, service context and the HCPs providing care to the patients. Another strength to the study was that the palliative care nurses have considerable experience in communication. Furthermore the field notes added to the results by providing insight into how the palliative care nurses were feeling when facilitating ACP supporting the overall findings of the study.

#### **4.1 Implications for practice**

This study demonstrates that facilitating ACP in the way it was done was acceptable to patients and their families. Opening the discussion in this way, with the aid of the booklet, in the second session

with a palliative care nurse, as part of a palliative care support service, also proved to be very supportive for the nurses in opening the discussion. This study supports research findings and guidelines from other countries that suggest that discussing ACP should be a part of routine practice for patients with a limited life expectancy. However, what needs to be considered is finding ways to achieve this. Training HCPs in communication and providing them with structure and tools to make them ready to initiate and facilitate ACP discussions is crucial to make ACP a part of care for patients with serious illness. This study also highlights that documentation, such as the booklet, can be helpful.

Based on the findings of this study, there is strong indication that including ACP in the palliative care support service for this patients group, facilitated by a palliative care nurse, is appropriate. The booklet also proved to be very supportive both for the nurses and the patients and their families. These findings will influence the practice of the HPCT who will consider from now on, for this to be part of their service. However, this study is only the first step in exploring ACP for patients and their families within the Icelandic health care system, and further research is needed.

## **4.2 Implications for research**

Even though the literature reveals that discussing ACP is helpful and several useful outcomes have been documented, there is little known about how Icelandic patients experience opening this discussion and therefore the researcher chose to start by studying their experience. The findings from this small qualitative study of patients' experience, is a step to provide insight and understanding into how ACP can be implemented into the health care service in Iceland. However, more studies are needed to gain further understanding. It would be very interesting to do a study that would include a longer follow up on the patients and family members who were offered the opportunity to engage in ACP. This would allow for more focus on the outcomes of ACP, such as whether the discussion influenced decision-making related to end of life care and treatment options. It would also allow for exploring the impact on family members and their bereavement. This study did not allow for focusing on outcome measures. However, there was some indication in this study that opening the ACP discussion, had guided decision-making related to care and treatment options for a patient in the support service. This patient had agreed to take part in the study, but when the research interview was to take place, had been admitted to hospital. Previously to this, in the second session with the support service when the ACP discussion was opened, the patient talked about his wishes for end of life, that he would prefer to die at home and that he did not want cardiopulmonary resuscitation. These wishes were taken into consideration as the patient expressed them clearly in the ACP discussion with the palliative care nurse. The researcher believes that having this discussion had an impact on how the patient was treated in hospital and shortened the stay in the hospital where a minimum of tests were done, and great effort was put into getting the patient home as quick as possible, where he died a week later.

This small study gives an indication that opening a discussion on ACP for this patients group in this setting is acceptable and further research need to be conducted to study outcomes of such a discussion. It is also important to conduct similar studies with a larger sample of patients, with other patients groups in nurse led outpatient clinics and in other settings.



## Conclusion

This study aimed to answer the question whether it is acceptable to open the discussion on ACP, as part of the palliative care support service, using the booklet *Thinking ahead – what is important to me*, for patients with advanced lung cancer as perceived by patients and families. The results support that the ACP discussion can be part of the palliative care support service for this group of patients, and palliative care nurses are ideally placed to facilitate the discussion. It was evident that by facilitating ACP 'routinely' during the second meeting with the palliative care nurse, for this patients group, was acceptable and appreciated by patients and families. With the aid of the booklet the nurses found it easier than expected to facilitate the discussion.



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## **Appendix**

Appendix 1: Booklet

Appendix 2: Framework for the support service

Appendix 3: Research interview guide

Appendix 4: Permission from the ethical board at Landspítali

Appendix 5: Permission from the Medical Director at Landspítali

Appendix 6: Letter of introduction

Appendix 7: Written consent

Appendix 8: Support from hospital chaplain





Það sem mér finnst mikilvægt

Þessi hluti snýr að óskum þínum og áherslum. Hann er ekki lagalega bindandi og þú getur hvenær sem er skipt um skoðun og breytt því sem þú hefur skrifað. Ef þú gerir breytingar, strikaðu þá yfir það sem þú skrifaðir áður og settu nýjan texta fyrir neðan. Það getur verið gagnlegt að setja tímasetningu við breytingar sem þú gerir.

Gagnlegt getur verið að láta heimilislækni, sérfræðing eða hjúkrunarfræðing sem er að sinna þér sjá hvað þú skrífir í þessum hluta. Þeir gætu viljað skrá þessar upplýsingar í sjúkraskrá með þínu leyfi.

Nafn:
Hvað veitir þér ánægju í lífinu núna og hvað angrar þig?
Hefur þú sérstakar óskir eða áherslur varðandi meðferð/umönnun þína í framtíðinni?

Hvaða skoðun hefurðu á endurlífgun?

Þegar hjartað hættir að slá og öndun hættir þá eru gerðar endurlífgunartilraunir. Það er ákvörðun læknis hvort endurlífgun skuli beitt og ef hann telur að endurlífgun muni ekki gagnast ræðir hann það við sjúkling og/eða aðstandendur og skráir í sjúkraskrá hans. Ef þetta hefur ekki verið rætt við þig en þú myndir vilja ræða það frekar eða fá meiri upplýsingar, talaðu þá við lækni eða hjúkrunarfræðing.


Undirskrift : \_\_\_\_\_

Dagsetning: \_\_\_\_\_

Undirskrift aðstandanda ( ef möguleg): \_\_\_\_\_

Nöfn heilbrigðisstarfsfólks sem tók þátt í umræðum við skrif í þennan blöðung


Hvar viltu helst deyja ef þú getur valið? Ef ástand þitt versnar, myndirðu vilja fá umönnun á spítala, á líknardeild, heima eða á hjúkrunarheimili? Þegar að þessum tíma kemur getur verið að þú getir ekki verið þar sem helst óskar þér vegna þess hve mikla umönnun þú þarft, ekki sé laust pláss eða þú hafir þörf fyrir rannsóknir á spítala. Það ætti hins vegar ekki að hindra þig í að setja fram óskir þínar.
Er eitthvað sem þú vilt taka fram, óskir eða áhyggjur, um hvaðeina, sem þú vilt að öðrum sé kunnugt um?
Er eitthvað sem þú þarft að fá meiri upplýsingar um? T.d. upplýsingar um réttindi þín
Hvað myndir þú helst vilja forðast að komi fyrir þig?
Höfum við gleymt einhverju?

Mikilvæg atriði

Hefurðu gert erfðaskrá? Já ☐ Nei ☐

Hafir þú sérstakar óskir um tilhögun eigna þinna utan skylduarfs er nauðsynlegt að gera erfðaskrá. Skylduerfingar erfa lögum samkvæmt allar eignir einstaklings eftir andlát hans. Þó er einstaklingi sem á skylduerfingja frjálst að ráðstafa allt að þriðjungu eigna sinna með erfðaskrá. Einstaklingum sem ekki eiga skylduerfingja er frjálst að ráðstafa öllum eignum sínum með erfðaskrá. Ef þú þarft aðstoð eða upplýsingar getur verið gagnlegt að leita til félagsráðgjafa eða lögfræðings. Þá er hægt að fá upplýsingar um erfðamál á vefnum; [www.island.is/thjonusta/efri-arin/q/undirflokkur/](http://www.island.is/thjonusta/efri-arin/q/undirflokkur/).

Hefurðu gert lífsskrá? Já ☐ Nei ☐

Lífsskrá er eyðublað þar sem óskum fólks varðandi meðferð við lífslok er komið á framfæri við þær aðstæður þegar það sjálft getur ekki tekið þátt í ákvörðunum um þá meðferð vegna andlegs eða líkamlegs ástands.

Í lífsskrá eru skráð tvö mikilvæg atriði, annars vegar óskir um meðferð við lok lífs, geti viðkomandi ekki tekið þátt í ákvörðunum sjálfur og hins vegar tilnefning talsmanns sem hefur verið valinn til að koma fram fyrir hönd viðkomandi. Talsmaður hefur verið valinn til að taka þátt í umræðum um óskir varðandi meðferð við lífslok, hvort heldur það er að þiggja, hafna eða hætta meðferð.

Upplýsingar um lífsskrá er að finna á vefnum á slóðinni: [www.landlaeknir.is/servlet/file/store93/item1781/Lifsskra\\_leidbeiningar.pdf](http://www.landlaeknir.is/servlet/file/store93/item1781/Lifsskra_leidbeiningar.pdf)

Talsmaður

Ef þú hefur valið þér talsmann í lífsskránni, hver er hann?

Nafn \_\_\_\_\_

Tengsl við þig \_\_\_\_\_ Símanúmer \_\_\_\_\_



Ég samþykki að heilbrigðisstarfsfólk sem sinnir mér fá upplýsingar sem skráðar eru í þennan blöðung:

Undirskrift: \_\_\_\_\_ Dags: \_\_\_\_\_

Mundu að yfirfara reglulega það sem þú skrifaðir svo það endurspegli óskir þínar á hverjum tíma og undirritaðu breytingar og settu við þær dagsetningu. Ég hef endurskoðað óskir minar og er sátt/ur við þær upplýsingar sem hér koma fram.

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

### Gátlisti yfir mikilvæg atriði

Hefur þú látið einhvern hafa upplýsingar um hvar þú geymir mikilvæg skjöl? Hérna er listi yfir skjöl sem þú gætir viljað gefa upplýsingar um.

		Hver veit hvar þetta er?
Viðskiptabanki:	<input type="checkbox"/>	
Bankareikningur:	<input type="checkbox"/>	
Tryggingaskilmálar	<input type="checkbox"/>	
Kreditkort	<input type="checkbox"/>	
Lífeyrir	<input type="checkbox"/>	
Vegabréf	<input type="checkbox"/>	
Lán	<input type="checkbox"/>	
Leiguskilmálar	<input type="checkbox"/>	
Erfðaskrá	<input type="checkbox"/>	
Lífsskrá	<input type="checkbox"/>	
Skipulag útfarar	<input type="checkbox"/>	
Önnur mikilvæg skjöl/tengiliðir	<input type="checkbox"/>	

### Skipulag útfarar

Sumir vilja láta aðra vita hvernig þeir vilja haga útför og öðrum málum eftir andlát. Ef þú vilt getur þú sett þessi atriði fram á þetta blað.

Sá/þeir sem ég vil að skipuleggi útför mína er/u:	
Mín ósk um útfararstofu er:	
Grafreitir sem ég vil vera jarðsett/ur í:	
Ég vil líkbrennslu	Já <input type="checkbox"/> Nei <input type="checkbox"/>
Ég vil að jarðarförin fari fram í:	
Ég vil að þessi tónlist verði flutt:	
Ég vil að þessi sálmar og ritningarorð verði flutt:	
Sá/sú sem ég vil að jarðsyngi mig, ef möguleiki er á því, er:	
Annað sem ég vil að komi fram er:	

ÚTGEFANDI: LANDSPÍTALI JANÚAR 2015  
BLÖÐUNGURINN HEITIR Á ENSKU: THINKING AHEAD – WHAT IS IMPORTANT TO ME OG ER FRÁ STRATHCARRON HOSPICE, SKOTLANDI.  
ÞYDDUR OG STAÐFÆRÐUR AF KRISTINU LÁRU ÓLAFSDÓTTUR 2014. HÖNNUN: KYNNINGARMÁL LSH/ÁIC



## Appendix 2: Framework for the support service

### Viðtalsrammi vegna stuðningsþjónustu líknarráðgjafarteymis LSH við sjúklinga með útbreitt lungnakrabbamein, 2014

#### FYRSTA VIÐTAL

Fylgja eftir upplýsingum um stuðningsþjónustuna, kynna innihald viðtalsins og tímamörk. Leita samþykkis hjá sjúklingi fyrir því sem þar mun fara fram (svara spurn. o.þ.h.)

#### Skilningur á / fræðsla um eðli sjúkdóms

##### **Kanna skilning á sjúkdómi og horfum**

*Geturðu lýst fyrir mér ástandi þínu núna?*

*Hvað hefur læknirinn rætt við þig um sjúkdóminn /veikindin/ stöðuna nú?*

*Hvaða skilning leggur þú í það?*

*Hvað hefur verið rætt um tilgang meðferðarinnar?*

*Aðrar útskýringar á meðferðarmarkmiðum*

*Hafið þið rætt um hvert skal stefna í meðferðinni?*

*Hvaða spurningar brenna helst á þér varðandi meðferðina?*

*Hversu mikið hefur þú skilið varðandi veikindi þín?*

*Er eitthvað sem er óskýrt/er eitthvað sem þú þarfnast skýringar á?*

*Hverskonar upplýsingar ertu helst í þörf fyrir núna?/hvað þarftu helst að fá að vita núna?*

#### Ákvarðanataka

##### **Spyrja um hvernig ákvörðun var tekin**

*Geturðu sagt mér frá því hvernig þið rædduð / komust að X niðurstöðu*

**Aðstoða við ákvarðanatöku varðandi meðferð ef þörf er á**

*Hefurðu þörf fyrir aðstoð við að.....*

#### Mat á einkennum

Einkenameðferð – mat með áherslu á algeng einkenni hjá þessum sjúklingahópi: verki, einkenni frá lungum (hósti, mæði), þreytu og svefntruflanir, geðslag (þunglyndi og kvíða) og einkenni frá meltingarfærum (lystarleysi, megrun, ógleði, uppköst, hægðatregðu).

Mælitæki lögð fyrir

— ESAS - vendipunktur; verkir 3, kvíði, depurð  $\geq 2$ , önnur einkenni 3-4

— DT

Skoða niðurstöðu úr mælitækjum og fá nánari upplýsingar um einkenni/vandamál sem koma fram. Taka einkennasögu um einkenni sem skora yfir vendipunkti á ESAS.

*Hvað plagar þig mest núna?*

*Hvaða þrjú vandamál telur þú að við getum helst hjálpað þér við?*

Fræðsla veitt um einkenni, meðferð einkenna, aukaverkanir, tengsl einkenna, fyrirbyggingu einkenna, lyfjanotkun, önnur úrræði en lyf við einkennum, mikilvægi hvíldar og hreyfingar og annað eftir þörfum.

#### Biargráð

##### **Sjúklings**

*Hvað hefur reynst þér best í erfiðum aðstæðum?*

*Hvað telurðu að nýtist þér best við þessar aðstæður?*

##### **Fjölskylda / umönnunaraðila**

*Hvað hefur reynst fjölskyldunni best í erfiðum aðstæðum?*

*Hvað telurðu að nýtist fjölskyldunni best við þessar aðstæður?*

*Stuðningur*

## **Viðtalsrammi vegna stuðningsþjónustu líknarráðgjafarteymis LSH við sjúklinga með útbreitt lungnakrabbamein, 2014**

### **Ráðleggingar**

Ráðleggingar veittar um úrræði sem bjóðast sjúklingum eins og t.d. Ljósíð, ráðgjafarþjónusta KÍ, stuðningshópur fólks sem greinst hefur með lungnakrabbamein, lungnakrabbamein.is, slökun á 11B og fleira. Almennar ráðleggingar um mataræði og hreyfingu.

### **Tilvísanir / lyfja-fyrirmæli / ávísanir**

Hjúkrunarfræðingar LRT fylla út beiðni um hjálpartæki ef þarf og fylgja beiðninni eftir og vísa á aðrar stöðstéttir með því að fylla út beiðni um ráðgjöf til viðeigandi aðila, s.s. félagsráðgjafa, sálfræðings. Þá sækja þeir um heimahjúkrun, heimsendan mat eða heimilishjálp eða aðstoða sjúkling við að gera það.

Hjúkrunarfræðingar LRT hafa samband við lækna stuðningsþjónustunnar til að ávísa lyfjum til einkennastíllingar. **Skrá öll samskipti rafrænt/ ávísa nýjum lyfjum rafrænt**

Hjúkrunarfræðingum LRT er heimilt að endurmeta skammta ógleðilyfja og ópíóíða til hækkunar án samráðs við lækna stuðningsþjónustunnar. Þá gilda eftirfarandi reglur:

Ópíóíðar: Hjúkrunarfræðingar mega gera hefðbundna 30% hækkun á ópíóíðaskammti ef einkenni sjúklings gefa tilefni til og engar frábendingar hafa verið skráðar af lækni.

Ógleðilyf: Hjúkrunarfræðingar mega hækka (t.d. tvöfalda) skammta ógleðilyfjanna, Afipran (metóklópramíð), Vogalene (metóprimazín) og Haldóls (halóperíðol).

### **Skipuleggja næstu komur til hjúkrunarfræðings/(læknis) líknarráðgjafarteymis (LRT)**

Endurkoma hjá hjúkrunarfræðingi eftir 4 vikur nema annað sé ákveðið. Ef um er að ræða mikil einkenni, er fenginn tími hjá lækni líknarráðgjafarteymis. Ef sjúklingur fær sérhæfða heimahjúkrun þá tekur hún við.

**Tilvísun í aðra þjónustu. LRT má vísa í sérhæfða heimahjúkrun án undangengins samþykkis krabbameinslæknis en þarf að upplýsa.**

*Vísad í heimaþjónustu að undangengnu mati á líðan og þörfum og hjargráðum*

### **Skráning í sjúkraskrá**

Skrá niðurstöður úr ESAS og DT undir mælitæki í Sögu. Skrá það sem fram kom í viðtali í göngudeildarnótu eftir sniðmáti sem hefur verið útbúið fyrir stuðningsþjónustu.

## Viðtalsrammi vegna stuðningsþjónustu líknarráðgjafarteymis LSH við sjúklinga með útbreitt lungnakrabbamein, 2014

### ANNAÐ VIÐTAL

#### Mat á einkennum

Mælitæki lögð fyrir

- ESAS - vendipunktur; verkir 3, kvíði, depurð  $\geq 2$ , önnur einkenni 3-4
- DT

Skoða niðurstöðu úr mælitækjum og fá nánari upplýsingar um einkenni/vandamál sem koma fram. Taka einkennasögu um einkenni sem skora yfir vendipunkti á ESAS.

- *Hvað plagar þig mest núna?*
- *Hvaða þrjú vandamál telur þú að við getum helst hjálpað þér við?*

Einkennameðferð – mat með áherslu á algeng einkenni hjá þessum sjúklingahópi: verki, einkenni frá lungum (hósti, mæði), þreytu og svefntruflanir, geðslag (þunglyndi og kvíða) og einkenni frá meltingarfærum (lystarleysi, megrun, ógleði, uppköst, hægðatregðu)

Fræðsla veitt um einkenni, meðferð einkenna, aukaverkanir, tengsl einkenna, fyrirbyggingu einkenna, lyfjanotkun, mikilvægi hvíldar og hreyfingar og annað eftir þörfum.

#### Tilvísanir / lyfja-fyrirmæli / ávísanir

Hjúkrunarfræðingar LRT fylla út beiðni um hjálpartæki ef þarf og fylgja beiðninni eftir og vísa á aðrar stöðstéttir með því að fylla út beiðni um ráðgjöf til viðeigandi aðila, s.s. félagsráðgjafa, sálfræðings. Þá sækja þeir um heimahjúkrun, heimsendan mat eða heimilishjálp eða aðstoða sjúkling við að gera það.

Hjúkrunarfræðingar LRT hafa samband við lækna stuðningsþjónustunnar til að ávísa lyfjum til einkennastíllínging. **Skrá öll samskipti rafrænt/ ávísa nýjum lyfjum rafrænt**

Hjúkrunarfræðingum LRT er heimilt að endurmeta skammta ógleðilyfja og ópíóíða til hækkunar án samráðs við lækna stuðningsþjónustunnar. Þá gilda eftirfarandi reglur:

Ópíóíðar: Hjúkrunarfræðingar mega gera hefðbundna 30% hækkun á ópíóíðaskammti ef einkenni sjúklings gefa tilefni til og engar frábendingar hafa verið skráðar af lækni.

Ógleðilyf: Hjúkrunarfræðingar mega hækka (t.d. tvöfalda) skammta ógleðilyfjanna, Afípran (metóklópramíð), Vogalene (metóprimazín) og Haldóls (halóperíðol).

#### Umræða um meðferðarmarkmið og framtíðina

Undirbúa samtalið með þessum inngangi: *Mig langar til að ræða hvað er framundan og kanna hvort þú vilt gera áætlun um framhaldið með því að horfa aðeins fram á við. Mikilvægt er að ræða þetta þegar vel gengur því það gefur okkur tíma til að ræða málin og þér og ykkur tækifæri til að hugsa og velja þessum hlutum fyrir ykkur. Og það gefur ykkur líka tækifæri til að undirbúa ykkur ef allt fer á versta veg. Til þess að hjálpa okkur við að ræða um þetta hefur verið útbúið skjal að skoskri fyrirmynd sem notað er til að hjálpa þér að koma á blað það sem þér finnst mikilvægt að koma á framfæri. Sýna skjalið.*

Fá samþykki fyrir að halda áfram. *Er í lagi að ræða þetta núna? Það að við séum að ræða þetta núna þýðir ekki að sjúkdómurinn sé að versna eða að það eigi að gera einhverjar breytingar. En þetta er alvarlegur sjúkdómur og gott að hafa sett upp plan ef hlutirnir fara ekki eins vel og við vonumst eftir. Tilgangurinn er að þú sagst okkur hvernig þú vilt helst hafa hlutina og hjálpa til ef taka þarf ákvörðun um framhaldið og þú ert of veikur til þess að taka þátt í umræðunni. Mig langar til að kynna þetta skjal fyrir ykkur og þú ræður auðvitað hvort þú fyllir það út en aðalatriðið er að það gefur okkur tækifæri til að ræða þetta. Fara í gegnum*

## **Viðtalsrammi vegna stuðningsþjónustu líknarráðgjafarteymis LSH við sjúklinga með útbreitt lungnakrabbamein, 2014**

blöðunginn blaðsíðu fyrir blaðsíðu og útskýra hvern hluta, bjóða sjúklingi og aðstandanda að spyrja spurninga.

Hér mætti nota spurningar eins og:

*Hvað er þér mikilvægast í lífinu núna?*

*Þegar þú hugsar til framtíðarinnar, hverjar eru helstu áhyggjur þínar?*

*Þegar þú hugsar um framtíðina hefur þú velt fyrir þér hvar þú myndir helst vilja fá umönnun ef sjúkdómurinn versnar?*

Að lokum kanna með þátttöku í viðtali vegna rannsóknar: *Hluti af rannsókninni á stuðningsþjónustunni sem er í gangi er að kanna reynslu fólks af því að eiga þessar samræður með því að nota þennan blöðung. Má hjúkrunarfræðingur hafa samband við ykkur á næstu dögum til að fá við ykkur viðtal um ykkar reynslu? Viðtalið getur farið fram heima hjá þátttakanda eða á göngudeild. Setja niður tíma ef það hentar annars hefur rannsakandi samband á næstu dögum.*

### **Skipuleggja næstu komur til hjúkrunarfræðings/(læknis) líknarráðgjafarteymis (LRT)**

Endurkoma hjá hjúkrunarfræðingi eftir 4 vikur nema annað sé ákveðið. Ef um er að ræða mikil einkenni, er fenginn tími hjá lækni. Ef sjúklingur fær sérhæfða heimahjúkrun þá tekur hún við.

**Tilvísun í aðra þjónustu. LRT má vísa í sérhæfða heimahjúkrun án undangengins samþykkis krabbameinslæknis en þarf að upplýsa.**

*Vísad í heimaþjónustu að undangengnu mati á liðan og þörfum og bjargráðum*

### **Skráning í sjúkraskrá**

Skrá niðurstöður úr ESAS og DT undir mælitæki í Sögu. Skrá það sem fram kom í viðtali í göngudeildarnótu eftir sniðmáti sem hefur verið útbúið fyrir stuðningsþjónustu.

## Viðtalsrammi vegna stuðningsþjónustu líknarráðgjafarteymis LSH við sjúklinga með útbreitt lungnakrabbamein, 2014

### ÞRIÐJA VIÐTAL

#### Mat á einkennum

Mælitæki lögð fyrir

- ESAS - vendipunktur; verkir 3, kvíði, depurð  $\geq 2$ , önnur einkenni 3-4
- DT

Skoða niðurstöðu úr mælitækjum og fá nánari upplýsingar um einkenni/vandamál sem koma fram. Taka einkennasögu um einkenni sem skora yfir vendipunkti á ESAS.

- *Hvað plagar þig mest núna?*
- *Hvaða þrjú vandamál telur þú að við getum helst hjálpað þér við?*

Einkennameðferð – mat með áherslu á algeng einkenni hjá þessum sjúklingahópi: verki, einkenni frá lungum (hósti, mæði), þreytu og svefntruflanir, geðslag (þunglyndi og kvíða) og einkenni frá meltingarfærum (lystarleysi, megrun, ógleði, uppköst, hægðatregðu).

Fræðsla veitt um einkenni, meðferð einkenna, aukaverkanir, tengsl einkenna, fyrirbyggingu einkenna, lyfjanotkun, mikilvægi hvíldar og hreyfingar og annað eftir þörfum.

#### Tilvísanir / lyfja-fyrirmæli / ávísanir

Hjúkrunarfræðingar LRT fylla út beiðni um hjálpartæki ef þarf og fylgja beiðninni eftir og vísa á aðrar stoðstéttir með því að fylla út beiðni um ráðgjöf til viðeigandi aðila, s.s. félagsráðgjafa, sálfræðings. Þá sækja þeir um heimahjúkrun, heimsendan mat eða heimilishjálp eða aðstoða sjúkling við að gera það.

Hjúkrunarfræðingar LRT hafa samband við lækna stuðningsþjónustunnar til að ávísa lyfjum til einkennastíllingar. **Skrá öll samskipti rafrænt/ ávísa nýjum lyfjum rafrænt**

Hjúkrunarfræðingum LRT er heimilt að endurmeta skammta ógleðilyfja og ópíóíða til hækkunar án samráðs við lækna stuðningsþjónustunnar. Þá gilda eftirfarandi reglur:

Ópíóíðar: Hjúkrunarfræðingar mega gera hefðbundna 30% hækkun á ópíóíðaskammti ef einkenni sjúklings gefa tilefni til og engar frábendingar hafa verið skráðar af lækni.

Ógleðilyf: Hjúkrunarfræðingar mega hækka (t.d. tvöfalda) skammta ógleðilyfjanna, Afipran (metóklópramíð), Vogalene (metóprimazín) og Haldóls (halóperíðol).

#### Umræða um meðferðarmarkmið og framtíðina: framhald

Kanna hvernig sjúklingi og aðstandanda fannst umræðan sem fór fram í öðru viðtali, hvort hann/þau vilja ræða þetta frekar eða fá upplýsingar og hvort sjúklingur hafi skráð í blöðunginn. *Í síðasta viðtali ræddum við um framtíðina og að gera plön um hvernig þú vilt hafa hlutina ef sjúkdómurinn versnar mikið. Hvernig var það fyrir þig/ykkur að ræða þetta? Hafið þið haldið áfram með þessa umræðu heima? Er eitthvað sem þig/ykkur langar að ræða meira um eða fá meiri upplýsingar? Eru einhverjar spurningar sem vöknudú? Heldurðu að það sé gagnlegt að ræða þetta og fylla út þetta skjal? Er eitthvað sem þú vilt að sé skráð í sjúkraskránnu þína?*

#### Skipuleggja næstu komur til hjúkrunarfræðings/(læknis) líknarráðgjafarteymis (LRT)

Endurkoma hjá hjúkrunarfræðingi eftir 4 vikur nema annað sé ákveðið. Ef um er að ræða mikil einkenni, er fenginn tími hjá lækni. Ef sjúklingur fær sérhæfða heimahjúkrun þá tekur hún við.

**Tilvísun í aðra þjónustu. LRT má vísa í sérhæfða heimahjúkrun án undangengins samþykkis krabbameinslæknis en þarf að upplýsa.**

*Vísad í heimajónustu að undangengnu mati á líðan og þörfum og bjargráðum*

#### Skráning í sjúkraskrá

Skrá niðurstöður úr ESAS og DT undir mælitæki í Sögu. Skrá það sem fram kom í viðtali í göngudeildarnótu eftir sniðmáti sem hefur verið útbúið fyrir stuðningsþjónustu.





## Appendix 3: Research interview guide

### Viðtalsrammi um reynslu af umræðu um áætlun um meðferðarmarkmið

Tilgangur viðtalsins er að kanna reynslu sjúklings og aðstandenda af umræðu um áætlun um meðferðarmarkmið og notkun blöðungs í þeim tilgangi. Þar sem verið er að bæta þessum hluta við stuðningsþjónustu LRT er mikilvægt að kanna fýsileika þess að gera þetta á þennan hátt og á þessum tímapunkti í sjúkdómsferlinu.

Við lok annars viðtals óskar hjúkrunarfræðingurinn eftir leyfi til að rannsakandi fái viðtal við sjúkling og aðstandenda ef það hentar til að ræða um reynslu þeirra af umræðu um áætlun um meðferðarmarkmið og blöðung sem notaður er í þeim tilgangi. Ef hægt er er ákveðinn tími fyrir viðtalið og ætlunin er að viðtalið fari fram innan tveggja vikna frá öðru viðtali í stuðningsþjónustu. Ef ekki er ákveðinn tími fyrir viðtal hefur rannsakandi samband við sjúkling innan þriggja daga til að ákveða tíma og staðsetningu fyrir viðtal. Boðið er upp á að viðtalið fari fram á heimili sjúklings eða á LIC allt eftir því hvað sjúklingnum finnst best. Viðtalið er hljóðritað og vélritað upp frá orði til orðs. Greinarmunur er gerður á svörum sjúklings og aðstandenda.

Inngangur að samtali: *Nú höfum við verið með stuðningsþjónustu við sjúklinga greinda með lungnakrabbamein frá því í mars og erum enn að þróa þjónustuna. Hluti af líknarmedferð er að gefa sjúklingum og aðstandendum færi á að segja frá óskum sínum og vilja varðandi framtíðarmedferð og í þeim tilgangi höfum við þýtt og staðfært þennan blöðung sem þið fenguð í síðasta viðtali. Vegna þess að þetta er ný nálgun hér á landi við að eiga þessa umræðu langar mig til að heyra af ykkar reynslu af því. Getur þú/þið lýst fyrir mér hvernig þér/ykkur fannst að ræða þessi mál og hvernig þér/ykkur fannst að hafa þennan blöðung til stuðnings við það?*

Þessar spurningar eru til að hefja samtalið og ef til vill fást miklar upplýsingar með því að spyrja þessara spurninga. Fleiri spurningar er hægt að spyrja ef svör við þeim hafa ekki þegar komið fram í viðtalinu.

*Rædduð þið þetta meira eftir að þið komuð heim?*

*Við hverja rædduð þið þetta?*

*Fylltirðu út í bæklinginn?*

*Hvað fylltirðu út?*

*Var eitthvað hjálplegra en annað?*

*Var eitthvað sem þér finnst að megi sleppa?*

*Hvað var óþægilegast að fylla út?*

*Hvað var erfiðast við að eiga þessa umræðu?*

*Hvað var hjálplegt við að eiga þessa umræðu?*

*Hvernig fannst þér að setja fram óskir þínar?*

Rannsakandi er meðvitaður um að þetta er viðkvæmt málefni sem getur valdið tilfinningaróti og þarf að vera næmur á líðan viðmælenda. Ef rannsakandi metur að viðmælendum líði illa vegna einhvers sem kom fram í viðtalinu þá býður hann þeim stuðning frá sr Guðlaugu Helgu sjúkrahúspresti.

Við lok viðtals þakkar rannsakandi þátttakendum fyrir.



## Appendix 4: Permission from the ethical board at Landspítali



Reykjavík, 27.nóvember 2014  
JSn/te

Valgerður Sigurðardóttir  
Yfirlæknir  
Líknardeild Kópavogi

**Varðar erindi 42/2014 „Áhrif stuðningsþjónustu líknarráðgjafateymis fyrir sjúklinga með nýgreint útbreitt lungnakrabbamein.“**

Ágæta Valgerður

Höfum móttengið svar þitt dags. 17.nóvember 2014 ásamt fylgigögnum og svarar þetta athugasemdum nefndarinnar með fullnægjandi hætti.

Endanlegt samþykki siðanefndar Landspítala fyrir ofangreinda rannsókn er hér með veitt.

Siðanefnd LSH bendir rannsakendum á að birta siðanefndarnúmer rannsóknarinnar þar sem vitnað er í leyfi nefndarinnar í birtum greinum um rannsóknina. Jafnframt fer Siðanefnd LSH fram á að fá send afrit af birtum greinum um rannsóknina.

Gangi þér vel við rannsóknarstörfin.

*Virðingarfyllst fyrir hönd siðanefndar Landspítala,*

*Tinna Eysteinsdóttir*

Tinna Eysteinsdóttir, forstöðumaður.

Siðanefnd Landspítala  
Vísinda- og þróunarviði  
Eirbergi, Eiríksgötu 34  
101 Reykjavík

Formaður: Jón Snædal  
Varaformaður: Elísabet Guðmundsdóttir  
Forstöðumaður: Tinna Eysteinsdóttir  
Tölvupóstur: [sidanefnd@landspitali.is](mailto:sidanefnd@landspitali.is)



## Appendix 5: Permission from the Chief Medical Officer at Landspítali



Kristín Lára Ólafsdóttir,  
hjúkrunarfræðingur/meistarani

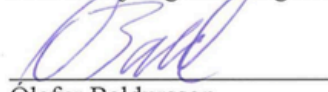
Reykjavík, 20. nóvember 2014  
Tilv.16, LSH 108-14 ÓB/ei

**Efni: Áhrif stuðningsþjónustu líknarráðgjafateymis fyrir sjúklinga með nýgreint útbreitt lungnakrabbamein**

Vísað er til erindis þíns til framkvæmdastjóra lækninga, dags. 13. nóvember sl. þar sem óskað er heimildar til að gera ofangreinda rannsókn á Landspítala. Fram kom að ábyrgðarmaður rannsóknarinnar er Valgerður Sigurðardóttir yfirlæknir líknardeildar Landspítala og samstarfsmenn eru Kristín Lára Ólafsdóttir hjúkrunarfræðingur og meistaranemi, Erna Haraldsdóttir fræðslustjóri á Strathcarron Hospice í Skotlandi, Helga Jónsdóttir, prófessor við hjúkrunarfræðideild HÍ, Nanna Friðriksdóttir, sérfræðingur í krabbameinshjúkrun, Arndís Jónsdóttir, sérfræðingur í líknarhjúkrun og Arna Dögg Einarsdóttir, sérfræðilæknir, allar starfsmenn LSH.

Hér með er veitt heimild til að ofangreind rannsókn fari fram á LSH og jafnframt er veittur aðgangur að sjúkraskrá sem tengjast kunna rannsókninni. Leyfi þetta er háð því að fyrir liggi samþykki siðanefndar Landspítala og Persónuverndar og mun aðgangur að sjúkraskrá verða opnaður þegar þær heimildir liggja fyrir.

Með kveðju og ósk um gott rannsóknargengi,

  
Ólafur Baldursson,  
framkvæmdastjóri lækninga

Samrit:

Valgerður Sigurðardóttir, yfirlæknir

Afrit:

Jón Snædal, formaður siðanefndar Landspítala  
Hjördís Stefánsdóttir, s. forstjóri Persónuverndar,  
Hlíf Steingrimsdóttir, framkvæmdastjóri  
Magnús Gottfreðsson, yfirlæknir vísindadeildar  
Ingibjörg Richter, kerfisfræðingur

FRAMKVÆMDASTJÓRI LÆKNINGA

LSH Eiríksgötu 5 • 101 Reykjavík • Sími 543 1103 • Fax 543 1112 • Netfang: [olafbald@landspitali.is](mailto:olafbald@landspitali.is) • [www.landspitali.is](http://www.landspitali.is)



## Appendix 6: Letter of introduction



HÁSKÓLI ÍSLANDS  
HEILBRIGÐISVÍSINDASVIÐ  
HJÚKRUNARFRÆÐIDEILD



### Kynning á vísindarannsókn:

#### Áhrif stuðningsþjónustu líknarráðgjafateymis fyrir sjúklinga með nýgreint útbreitt lungnakrabbamein

Ágæti viðtakandi

Tilgangur rannsóknarinnar er að meta áhrif stuðningsþjónustu líknarráðgjafateymis fyrir sjúklinga sem greinst hafa með lungnakrabbamein og meta fýsileika þess að opna umræðu um áætlun um meðferðarmarkmið sem hluta af stuðningsþjónustu. Sjúklingar í samanburðarhópi eru með krabbamein annars staðar en í lungum. Þér er boðið að taka þátt í rannsókninni þar sem þú ert að þiggja krabbameinslyfjameðferð eftir að hafa greinst með krabbamein. Hafnir þú þátttöku í rannsókn hefur það ekki áhrif á þá þjónustu sem þér stendur til boða.

Ábyrgðarmaður:

Valgerður Sigurðardóttir, dr. med.

Kennitala: 270452-3619

Staða: Yfirlæknir á líknardeild Landspítalans

Sími: 543 6337 Aðsetur: Líknardeild í Kópavogi Netfang: [valgersi@landspitali.is](mailto:valgersi@landspitali.is)

Aðalrannsakandi:

Kristín Lára Ólafsdóttir

Kennitala: 100873-5409

Staða: Hjúkrunarfræðingur og meistaranemi við Hjúkrunarfræðideild Háskóla Íslands

Sími: 543 6070 Netfang: [kristinl@landspitali.is](mailto:kristinl@landspitali.is)

Rannsóknarhópur:

Erna Haraldsdóttir, gestaprófessor við hjúkrunarfræðideild HÍ, Helga Jónsdóttir, prófessor við hjúkrunarfræðideild HÍ, Nanna Friðriksdóttir, sérfræðingur í krabbameinshjúkrun á Landspítala, Arndís Jónsdóttir, sérfræðingur í líknarhjúkrun á Landspítala og Arna Dögg Einarsdóttir, sérfræðingur í almennum lyflækningum.

### Þátttakendur

Þátttakendur í þessari rannsókn eru sjúklingar sem greinst hafa með krabbamein og fá krabbameinslyfjameðferð á dag- og göngudeild krabbameinslækninga 11B. Þátttakendur eru ýmist í meðferðarhópi eða samanburðarhópi.

- Þátttakendur í meðferðarhópi eru sjúklingar sem greinst hafa með útbreitt lungnakrabbamein og fá stuðningsþjónustu líknarráðgjafateymis samhliða hefðbundinni krabbameinsmeðferð. Stuðningsþjónustan er veitt í formi viðtala á 4-6 vikna fresti þar sem gert er mat á einkennum, lögð til meðferð við þeim og rætt um tilgang meðferðar og óskir sjúklings og aðstandenda. Hvert viðtal stendur yfir í 45-60 mínútur og gert er ráð fyrir að aðstandendur séu með í viðtölum sé þess kostur. Tveir hjúkrunarfræðingur veita þjónustuna sem lýst hefur verið. Annar er rannsakandi og hefur langa reynslu af sérhæftri líknarhjúkrun og hinn hjúkrunarfræðingurinn er sérfræðingur í líknarhjúkrun og hefur áratuga langa starfsreynslu.
- Þátttakendur í samanburðarhópi eru sjúklingar sem greinst hafa með krabbamein annars staðar en í lungum og fá hefðbundna krabbameinsmeðferð.

Báðir hópar eru beðnir að svara þremur spurningalistum í byrjun meðferðar, eftir 10-12 vikur og eftir 14-16 vikur. Þátttakendur fá listana afhenta þegar þeir koma til meðferðar á dag- og göngudeild krabbameinslækninga 11B og geta ýmist valið að svara á staðnum eða heima. Listunum er hægt að skila í kassa á 11B eða senda í pósti þar sem frímerkt umslag fylgir þeim.

Óskað verður eftir því við þátttakendur í meðferðarhópi að rannsakandi fái að taka sérstakt viðtal við þá og aðstandendur þeirra þar sem rætt er um reynslu þeirra af umræðu um óskir og vilja varðandi framtíðarmeðferð.

Þátttaka felur einnig í sér að rannsakandi fær leyfi til að safna gögnum úr sjúkraskrá sjúklings er varða núverandi veikindi, kyn, aldur, sjúkdómsgreiningu, einkenni, líðan, krabbameinsmeðferð, aðra þjónustu og meðferðarmarkmið.

### Ávinningur

Þess er vænst að niðurstöður varpi ljósi á áhrif stuðningsþjónustu líknarráðgjafateymis og vonast er til að hægt verði að þróa og bæta þjónustu fyrir sjúklinga sem greinast með útbreitt krabbamein.

### Nafnleynd og trúnaði heitið

Nafnleynd er heitið og ekki verður hægt að rekja neinar upplýsingar til þátttakenda. Gögnin verða í vörslu rannsakenda þar til að lokinni úrvinnslu og eytt að henni lokinni. Niðurstöður rannsóknarinnar verða birtar í lokaverkefni rannsakanda til meistaraþrófs í hjúkrunarfræði við Háskóla Íslands og í vísindatímaritum.

Þátttaka í rannsókninni hefur hverfandi áhættu í för með sér. Finni þátttakandi fyrir vanlíðan tengt þátttöku í rannsókninni býðst honum að þiggja stuðning frá sálsgæsluáðila.


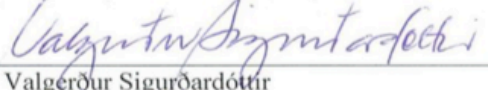
Þér ber engin skylda til að taka þátt í þessari vísindarannsókn. Þú getur hætt þátttöku hvenær sem er án eftirmála og það mun ekki hafa áhrif á þá heilbrigðisþjónustu sem þú kannt að fá í framtíðinni.

Rannsóknin hefur hlotið samþykki siðanefndar Landspítala og verið tilkynnt til Persónuverndar. Þátttakendur greiða engan kostnað af þátttöku í rannsókninni og fá ekki greitt fyrir þátttöku.

Frekari upplýsingar veitir Kristín Lára Ólafsdóttir, hjúkrunarfræðingur í síma 543 6070, netfang: [kristinl@landspitali.is](mailto:kristinl@landspitali.is) eða Valgerður Sigurðardóttir, læknir í síma 543 6337, netfang: [valgersi@landspitali.is](mailto:valgersi@landspitali.is)

Kærar þakkir fyrir að íhuga þátttöku í þessari rannsókn

Reykjavík, nóvember 2014

 Kristín Lára Ólafsdóttir hjúkrunarfræðingur	 Valgerður Sigurðardóttir yfirlæknir
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*Ef þú hefur spurningar um rétt þinn sem þátttakandi í þessari vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til siðanefndar Landspítala - háskólasjúkrahúss, Eirbergi, Eiríksgötu 34, 101 Reykjavík. Sími: 543 7465, tölvupóstur: [siðanefnd@landspitali.is](mailto:siðanefnd@landspitali.is).*



## Appendix 7: Written consent



HÁSKÓLI ÍSLANDS  
HEILBRIGÐISVÍSINDASVIÐ  
HJÚKRUNARFRÆÐIDEILD



### Upplýst samþykki fyrir þátttöku í vísindarannsókninni Áhrif stuðningsþjónustu líknarráðgjafateymis fyrir sjúklinga með nýgreint útbreitt lungnakrabbamein

Tilgangur rannsóknarinnar er að meta áhrif stuðningsþjónustu líknarráðgjafateymis fyrir sjúklinga sem greinst hafa með lungnakrabbamein og meta fýsileika þess að opna umræðu um áætlun um meðferðarmarkmið sem hluta af stuðningsþjónustu.

Ábyrgðarmaður:

Dr. Valgerður Sigurðardóttir

Kennitala: 270452-3619

Staða: Yfirlæknir á líknardeild Landspítalans

Sími: 543 6337 Aðsetur: Líknardeild í Kópavogi Netfang: [valgersi@landspitali.is](mailto:valgersi@landspitali.is)

Aðalrannsakandi:

Kristín Lára Ólafsdóttir

Kennitala: 100873-5409

Staða: Hjúkrunarfræðingur og meistaranemi í Hjúkrunarfræðideild Háskóla Íslands

Sími: 543 6070 Netfang: [kristinl@landspitali.is](mailto:kristinl@landspitali.is)

Rannsóknarhópur:

Erna Haraldsdóttir, gestaprófessor við hjúkrunarfræðideild HÍ, Helga Jónsdóttir, prófessor við hjúkrunarfræðideild HÍ, Nanna Friðriksdóttir, sérfræðingur í krabbameinshjúkrun á Landspítala, Arndís Jónsdóttir, sérfræðingur í líknarhjúkrun á Landspítala og Arna Dögg Einarsdóttir, sérfræðingur í almennum lyflækningum.

### Þátttakendur

Þátttakendur í þessari rannsókn eru sjúklingar sem greinst hafa með krabbamein og fá krabbameinslyfjameðferð á dag- og göngudeild krabbameinslækninga 11B. Þátttakendur eru ýmist í meðferðarhópi eða samanburðarhópi.

- Þátttakendur í meðferðarhópi eru sjúklingar sem greinst hafa með útbreitt lungnakrabbamein og fá stuðningsþjónustu líknarráðgjafateymis samhliða hefðbundinni krabbameinsmeðferð. Stuðningsþjónustan er veitt í formi viðtala á 4 vikna fresti þar sem gert er mat á einkennum, lögð til meðferð við þeim og rætt um tilgang meðferðar og óskir sjúklings og aðstandenda. Hvert viðtal stendur yfir í 45-60 mínútur og gert er ráð fyrir að aðstandendur séu með í viðtölum sé þess kostur. Tveir hjúkrunarfræðingur veita þjónustuna sem lýst hefur verið. Annar er rannsakandi og hefur langa reynslu af sérhæftri líknarhjúkrun og hinn hjúkrunarfræðingurinn er sérfræðingur í líknarhjúkrun og hefur áratuga langa starfsreynslu.
- Þátttakendur í samanburðarhópi eru sjúklingar sem greinst hafa með krabbamein annars staðar en í lungum og fá hefðbundna krabbameinsmeðferð.

Báðir hópar eru beðnir að svara þremur spurningalistum í byrjun meðferðar, eftir 10-12 vikur og eftir 14-16 vikur. Þátttakendur fá listana afhenta þegar þeir koma til meðferðar á dag- og göngudeild krabbameinslækninga 11B og geta ýmist valið að svara á staðnum eða heima. Listunum er hægt að skila í kassa á 11B eða senda í pósti þar sem frimerkt umslag fylgir þeim. Óskað verður eftir því við þátttakendur í meðferðarhópi að rannsakandi fái að taka sérstakt viðtal við þá og aðstandendur þeirra þar sem rætt er um reynslu þeirra af umræðu um óskir og vilja varðandi framtíðarmeðferð.

Þátttaka felur einnig í sér að rannsakandi fær leyfi til að safna gögnum úr sjúkraskrá sjúklings er varða núverandi veikindi, kyn, aldur, sjúkdómsgreiningu, einkenni, líðan, krabbameinsmeðferð, aðra þjónustu og meðferðarmarkmið.

### Ávinningur

Þess er vænst að niðurstöður varpi ljósi á áhrif stuðningsþjónustu líknarráðgjafateymis og vonast er til að hægt verði að þróa og bæta þjónustu fyrir sjúklinga sem greinast með útbreitt krabbamein.

### Nafnleynd og trúnaði heitið

Nafnleynd er heitið og ekki verður hægt að rekja neinar upplýsingar til þátttakenda. Gögnin verða í vörslu rannsakenda þar til að lokinni úrvinnslu og eytt að henni lokinni. Niðurstöður rannsóknarinnar verða birtar í lokaverkefni rannsakanda til meistaraprófs í hjúkrunarfræði við Háskóla Íslands og í vísindatímaritum. Þátttaka í rannsókninni hefur hverfandi áhættu í för með sér. Finni þátttakandi fyrir vanlíðan tengt þátttöku í rannsókninni býðst honum að þiggja stuðning frá sálsgæsluaðila.

Rannsóknin hefur hlotið samþykki siðanefndar Landspítala og tilkynnt til Persónuverndar. Þátttakendur greiða engan kostnað af þátttöku í rannsókninni og fá ekki greitt fyrir þátttöku.

Upplýst samþykki fyrir þátttöku er í tvíriti og mun þátttakandi halda eftir öðru eintakinu. Þátttakandi tekur þátt í rannsókninni af fúsum og frjálsum vilja. Þátttakanda er frjálst að svara/svara ekki hverri spurningu spurningalistanna. Þátttakanda er frjálst að hafna þátttöku eða draga sig út úr henni hvenær sem hann vill. Ákvörðunin mun ekki á neinn hátt hafa áhrif á þá heilbrigðisþjónustu sem hann kann að fá í framtíðinni.

Ef þátttakandi hefur frekari spurningar getur hann haft samband við Kristínu Láru Ólafsdóttur í síma 543-6070, netfang [kristinl@landspitali.is](mailto:kristinl@landspitali.is) og Valgerði Sigurðardóttir, yfirlækni á líknardeild í Kópavogi sem er ábyrgðarmaður rannsóknarinnar í síma 543-6337, netfang [valgersi@landspitali.is](mailto:valgersi@landspitali.is).

Mér hefur verið kynntur tilgangur þessarar vísindarannsóknar og í hverju þátttaka mín er fölginn.

Ég er samþykk(ur) eftirfarandi þátttöku: svara spurningalistum, gefa rannsakanda leyfi til að skoða gögn í sjúkraskrá og leyfi til að óska eftir viðtali

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Dagsetning

Undirskrift þátttakanda

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Undirskrift þess sem leggur samþykkið fyrir f.h. ábyrgðarmanns rannsóknarinnar.

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*Ef þú hefur spurningar um rétt þinn sem þátttakandi í þessari vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til siðanefndar Landspítala - háskólasjúkrahúss, Eirbergi, Eiríksstöðu 34, 101 Reykjavík. Sími: 543 7465, tölvupóstur: [sidanefnd@landspitali.is](mailto:sidanefnd@landspitali.is).*

## Appendix 8: Support from hospital chaplain

Varðandi tilvísun vegna rannsóknar  
Guðlaug Helga Ásgeirsdóttir

to:

Kristín Lára Ólafsdóttir

03.11.2014 09:38

Hide Details

From: Guðlaug Helga Ásgeirsdóttir/LYF/Landspítali/IS

To: Kristín Lára Ólafsdóttir/LYF/Landspítali/IS@Landspítali

Varðandi rannsóknina: Áhrif stuðningsþjónustu líknarráðgjafateymis fyrir sjúklinga með nýgreint útbreitt lungnakrabbamein.

Rannsóknaraðili: Kristín Lára Ólafsdóttir.

Undirrituð, Guðlaug Helga Ásgeirsdóttir, sjúkrahúsprestur þjóðkirkjunnar, á líknardeild LSH Kópavogi, hefur móttengið beiðni frá Kristínu Láru Ólafsdóttur um að taka á móti þátttakendum í ofangreindri rannsókn í sálgæsluviðtöl ef þeir óska þess.

Ég veiti hér með góðfúslega leyfi til þess að þátttakendum sé vísað á mig og er tilbúin til þess að gefa þeim sálgæsluviðtöl ef þess er óskað.

Virðingarfyllt,

Guðlaug Helga Ásgeirsdóttir  
Sjúkrahúsprestur þjóðkirkjunnar  
Líknardeild LSH  
Kópavogi

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