MASTER THESIS

SHARED DECISION-MAKING IN PALLIATIVE CANCER CARE: A LIFE SPAN PERSPECTIVE

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‘Het meenemen van de patiëntvoorkeur om een bepaalde behandeling wel of niet te ondergaan is een belangrijk onderdeel. Kwaliteit van leven is, zeker ook voor de oudere patiëntengroep, een goede leidraad’.

Dr. Huub Maas, geriater in het TweeSteden Ziekenhuis te Tilburg, bestuurslid GeriOnNe

‘Communicatie met ouderen vraagt om specifieke vaardigheden’.

dr. A.N.M. Wymenga et al., Handboek Kanker bij Ouderen

‘In 2011 werd bij ruim 100.000 Nederlanders kanker vastgesteld. In 59% van de gevallen ging het om personen van 65 jaar en ouder’.

Nederlandse Kankerregistratie

‘De aandacht voor kanker bij ouderen schiet ernstig tekort’.

Michel Rudolphie, Algemeen directeur KWF Kankerbestrijding

‘Ouderen verliezen eerder hun familie en vrienden. Als je daar kanker aan toevoegt, is er sprake van de double-whammy’.

Prof. Dr. Jimmie C. Holland, psycho-oncoloog, Sloan Kettering Institute, New York

‘In 1950 was iemand van zestig oud. Nu is iemand van tachtig oud en over tien jaar kan dat iemand van honderd zijn. Ouderdom is daarnaast niet gedefinieerd door ‘kalenderleeftijd’ maar hoe iemand biologisch is’.

Prof. dr. Emile E. Voest, hoogleraar Medische Oncologie, UMC Utrecht, voorzitter Wetenschappelijke raad

‘Het bewijs voor richtlijnen is veelal gebaseerd op onderzoek bij patiënten van middelbare leeftijd, zonder comorbiditeit en andere beperkingen’.

dr. A.N.M. Wymenga et al., Handboek Kanker bij Ouderen

Source: KWF Kankerbestrijding (2013)

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Claudia Groot Kormelinck,

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CONTENTS

ABSTRACT

Background: Shared decision-making (SDM) is advocated in particular towards 1) elderly cancer patients, since treatment strategy depends on individual patient characteristics and preferences, and 2) in a palliative setting, where medical decision-making (MDM) involves a trade-off between quantity / quality of life. However, the MDM process in older cancer patients is not clearly understood and knowledge is scarce with regards to the feasibility of SDM in palliative cancer care. Moreover, studies suggest age-based differences in patients' level of involvement in MDM, yet it remains unclear *how* age affects the MDM process.

Aim: This study assesses the influence of age on patients preferences, perceived participation and levels of concordance (match between preferences and perceived participation) in MDM. Age-related aspects and demographics are explored as correlates. A life span perspective is used to study similarities / differences across three age groups, being 'middle aged-' (40-64 years), 'young elderly-' (65-74 years) and 'old elderly' ($\geq$ 75 years) patients facing metastatic cancers, who have chosen whether or not to pursue (life-prolonging) chemotherapy.

Method: The study design is quantitative, cross-sectional and retrospective. A paper and pencil questionnaire assessed (among others) patients' health-related quality of life, self-efficacy in communicating with oncologists', loneliness and temporal perspective as possible correlates towards participation in MDM.

Results: Patients' preferred-, perceived participation roles and levels of concordance were not age-related. A striking majority of both 'young-' and 'old elderly' patients preferred a patient centered approach and a majority of all age groups perceived the MDM as patient centered. Almost 20% of the patients was less involved than preferred in MDM. 'Old elderly' patients were significantly less encouraged to talk about worries as compared to 'middle aged' patients. Perceived SDM was associated with higher levels of self-efficacy in communication with oncologists and female gender.

Discussion: No evidence was found for age-related differences with regards to participation in MDM, probably due to the palliative nature of this study. If clinical practice aims to fit preferences better towards actual involvement, patients preferences should be literally asked for by oncologists, so that each can achieve their preferred level of involvement and treatments are tailored with respect to patient characteristics and preferences.

SAMENVATTING

Achtergrond: Gedeelde besluitvorming (SDM) wordt bepleit bij 1) oudere kankerpatiënten, waar behandelkeuzes afhangen van individuele patiënt kenmerken en voorkeuren en 2) in een palliatieve setting, waar medische besluitvorming (MDM) een afweging omvat tussen kwantiteit / kwaliteit van leven. Kennis over MDM bij oudere kankerpatiënten – evenals de geschiktheid van SDM in de palliatieve kankerzorg is schaars. Bovendien suggereren onderzoeken leeftijdsgerelateerde verschillen in de mate waarin patiënten betrokken zijn bij MDM, maar onduidelijk is *hoe* leeftijd van invloed is op het MDM proces.

Doel: Deze studie onderzoekt de invloed van leeftijd op patiënt voorkeuren- waargenomen participatie en de mate van overeenstemming hiertussen in MDM. Leeftijdsgerelateerde aspecten en demografische gegevens zijn onderzocht als mogelijke correlaten. Een levensloop perspectief is gebruikt om overeenkomsten / verschillen tussen drie leeftijdsgroepen te onderzoeken: ‘middelbare-’ (40-64 jaar), ‘jonge oudere-’ (65-74 jaar) en ‘oude oudere’ (≥ 75 jaar) patiënten met een gemetastaseerde vorm van kanker, die voor de keuze hebben gestaan om al dan niet een (levensverlengende) chemokuur te ondergaan.

Methode: Het onderzoeksdesign is kwantitatief, cross-sectioneel en retrospectief. Middels een schriftelijke zelfrapportage vragenlijst werd o.a. gevraagd naar gezondheidsgerelateerde kwaliteit van leven, self-efficacy in communicatie met de oncoloog, eenzaamheid en tijdsperspectief, als mogelijke correlaten van participatie in MDM.

Resultaten: Patiënt voorkeuren, waargenomen participatie en de mate van overeenstemming hiertussen waren niet leeftijdsgerelateerd. Een opvallende meerderheid van de ‘jonge-’ en ‘oude oudere’ patiënten prefereerde een patiënt gecentreerde rol en een meerderheid binnen alle leeftijdsgroepen heeft de MDM waargenomen als patiënt gecentreerd. Bijna 20% van de patiënten heeft minder betrokkenheid ervaren in MDM dan gewenst. ‘Oude oudere’ patiënten werden significant minder aangemoedigd om te praten over hun zorgen dan patiënten van middelbare leeftijd. Waargenomen SDM was geassocieerd met hogere niveaus van self-efficacy in communicatie met de oncoloog en vrouwelijk geslacht.

Discussie: Leeftijdsgerelateerde verschillen met betrekking tot participatie in MDM werden niet gevonden, waarschijnlijk door de palliatieve setting. Indien de klinische praktijk ernaar streeft voorkeuren beter te laten aansluiten bij daadwerkelijke participatie, zouden oncologen letterlijk naar voorkeuren moeten vragen, zodat iedere patiënt zijn gewenste niveau van betrokkenheid kan bereiken en behandelingen worden afgestemd op individuele patiënt kenmerken en voorkeuren.

1. INTRODUCTION

1.1 Cancer: an age-related disease

Cancer is the primary cause of death in the Netherlands since 2008 (CBS, 2009). The thought that death is inevitable when having cancer, leaves cancer one of the most feared diseases (Powe & Finnie, 2003). However, survival rates of cancer patients have increased due to the detection of cancer at an earlier stage and more effective treatments (Gommer, 2014). On the contrary, it is expected that the number of new cancer patients in the Netherlands will continue to rise with 3 percent each year, causing an increased prevalence of cancer (Integraal Kanker Centrum Nederland, 2014).

The most significant increase in the number of cancer patients can be found among the elderly, since the ability to correct errors in cell division is reduced as people age (Edwards et al., 2002; Repetto et al., 2003). Hence, 60% of all cancer patients is over 65 years and 25% is over 75 years (Wymenga, Coebergh, Maas & Schouten, 2012; KWF Kankerbestrijding, 2011). Due to the aging population, a further increase in the number of elderly cancer patients is expected in the coming decades (KWF Kankerbestrijding, 2011). Consequently, clinicians of industrialized countries have to treat an increasing number of elderly cancer patients (Repetto et al., 2003). Although cancer is most prevalent among the elderly, studies that focus on elderly cancer patients are scarce. They are often excluded from clinical research due to large differences in life expectancy and frailty. Therefore, conducting research among this age group is less attractive and little is known about elderly cancer patients (Wymenga et al., 2012; KWF Kankerbestrijding, 2010). This study fills this gap by focusing on elderly cancer patients.

1.2 Treatment of elderly cancer patients

Oncologists face difficulties making optimal treatment choices for elderly cancer patients. Due to the little amount of research, evidence-based guidelines for elderly cancer patients are lacking, providing physicians with little guidance and resulting in a great variability in treatment approaches (Puts et al., 2010).

In addition, as people age, they can experience constraints in areas such as comorbidity: *the simultaneous occurrence of two or more diseases* (Heijmans, Rijken, Schellevis & van den Bos, 2003), polypharmacy: *the simultaneous use of multiple medications* (Veehof, Haaijer-Ruskamp & Meyboom-De Jong, 2001) and overall functioning. People are considered as 'increased frail', as people experience more limitations in these areas (Wymenga et al., 2012). Although elderly cancer patients are not by definition 'frail', it is known for example that almost 70% of Dutch cancer patients aged 65-79 years and 80% of patients over 80 years have to deal with life-shortening comorbidity at time of diagnosis (Wymenga et al., 2012). These can include diabetes, heart disease and reduced organ functions (Maas, Janssen-Heijnen, Olde Rikkert & Wymenga, 2007; Lees & Chan, 2011). As a result, in most cases it remains unclear to what extent treatments are effective and elderly patients can experience more toxicities, due to a lack of knowledge about the interaction of the treatment with tumor characteristics and possible frailty (Wymenga et al., 2012).

> *‘A challenge for cancer specialists is to determine the optimum treatment for elderly patients- a heterogeneous population with regard to comorbidity, physical reserves, disability and geriatric conditions.’* (Hamaker et al., 2012, p.437)

With little data from clinical trials, physicians typically make treatment decisions based on the elderly patients’ functional status and life expectancy (Elkin, Kim, Casper, Kissane & Schrag, 2007). The recognition of frail and vital elderly patients should be a major focus for applying treatments among elderly cancer patients. For vital, elderly people it can still be worthwhile to opt for quantity of life, while frail people may choose to maintain quality of life (Wymenga et al., 2012).

In addition, physicians tent to determine patients’ own treatment preferences, since the choice between quantity or quality of life is a subjective trade-off (Elkin et al., 2007). However, physicians find it hard to determine patients’ treatment preferences (Robinson & Thomson, 2001; Puts et al., 2010). In clinical practice, it becomes prevalent that physicians often decide for other treatment choices than patients (KWF Kankerbestrijding, 2010). While many patients choose for maintaining quality of life, physicians often focus on the highest chance of cure (De Haes & Koedoot, 2003; Stalmeier et al., 2009).

Finding appropriate treatments for elderly cancer patients is therefore complex and involves a quest for tailored care. Hence, including patient preferences – and patient participation is a good directive in medical decision-making (MDM) among elderly cancer patients (Wymenga et al., 2012).

1.3 Implications for medical decision-making

Shared decision-making (SDM) is widely advocated as a ‘best-practice’ in cancer care (Thorne, Oliffe, & Stajduhar, 2013). It has potential positive outcomes, such as more active patient involvement, knowledge gain, more confidence in decisions (Stacey et al., 2014), increased patient satisfaction and improved health behaviors and disease management (Weiss & Peters, 2008). SDM is defined as:

> *'An approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.'* (Elwyn et al., 2012, p 1361)

In general, SDM is advocated as an appropriate approach for involving patients in MDM (Simon, Loh & Härter, 2007). SDM has been advocated in particular among elderly cancer patients, where choices of treatment strategy depend on individual patient characteristics and preferences (Elkin et al., 2007; Emanuel & Emanuel, 1992). However, the MDM process in older adults with cancer is not clearly understood. This is partly due to the limited studies which systematically examine patient related factors that influence the MDM process (Tariman, Berry, Cochrane, Doorenbos & Schepp, 2012). Also, the aforementioned under-representation of older adults in clinical trials may contribute to the limited understanding of the MDM process in this patient population (Di Maio & Perrone, 2003).

Furthermore, within Dutch cancer care, the impression exists that SDM between elderly cancer patients and physicians is more wish than reality. Therefore, the MDM process between physicians and elderly patients deserves more attention (Wymenga et al., 2012).

This present study focuses on SDM in cancer care, since more insight is needed into the extent to which SDM is embedded in clinical practice, especially with regards to elderly cancer patients. Moreover, studies have suggested age-based differences in both patients' perceptions and preferred level of involvement in MDM, yet it remains unclear how age affects the MDM process (Price, Bereknyei, Kuby, Levinson & Braddock, 2012; DeVoe, Wallace & Fryer, 2009). Therefore, aim of this is study to assess age-based differences in MDM, using a life span perspective. By including three age groups, being 'middle aged-' (40-64 years), 'young elderly-'(65-74 years) and 'old elderly' ($\geq$ 75 years) patients, this study examines whether there is a relationship between the life stages in which patients find themselves and preferred-, perceived participation as well as concordance (match between preferred – and perceived participation) in MDM.

The life span perspective of Grootenhuis and Bode (2010) has an individual-oriented focus, stating that when someone is confronted with disease, people will face different consequences and effects, depending on the life stage wherein someone is located. As people age, they face different developmental tasks. 'Middle aged' patients often experience a career peak and cancer in this stage of life can lead to feelings of shortcoming in fulfilling various roles (Grootenhuis & Bode, 2010). As people become older, they shift from a future oriented time perspective, towards shorter time perspectives for their goals and become more selectively in their goals and activities. Consequently, elderly patients are expected to be less concerned with being in control and less likely to manage an active coping style (O.Blank & Bellizzi, 2008). By consequence, this shows that age affects how people cope with illnesses such as cancer. Given the various age stages, theory supports the specific age classification of elderly cancer patients by closely examining differences between 'older' and 'younger' elderly populations (DeVoe et al., 2009).

1.4 Palliative chemotherapy

This study aims to yield more information about the extent to which SDM in palliative cancer care is preferred and prevalent, since little attention has been paid to SDM in palliative cancer care, where curing patients is no longer possible (Brom et al., 2014). The present study contributes to this lack of knowledge, by focusing on patients with metastatic cancers as target group and the decision whether or not to enter (life prolonging) chemotherapy. Moreover, SDM is especially suitable in palliative cancer care for two reasons.

First, death is often preceded by medical decisions to withhold or withdraw treatment. Especially in the absence of a cure, pursuing treatments (such as chemotherapy) might prolong life, however with the possibility of side effects, reducing patients' quality of life (Brom et al., 2014; Wymenga et al., 2012; Pardon et al., 2012). Therefore, patients' autonomy towards this choice has to be respected and MDM in a palliative setting cannot operate without examining personal preferences (Wymenga et al., 2012).

Second, concerns exist that patients' comprehension of the outcomes of chemotherapy may be overly optimistic (Weeks et al., 1998) and patients facing metastatic cancers might be willing to accept chemotherapy even if it provides a small chance and short duration of benefits (Balmer, Thomas & Osborne, 2001). Hence, it is important that patients receive appropriate information about their prognosis and the likely outcomes of treatment. This process of informed decision-making can be facilitated by involving patients in the MDM process (Grunfeld et al., 2006).

However, questions have been raised towards the usefulness of SDM in the palliative setting. Seriously ill patients might not put a high value on autonomy in MDM and prefer to delegate control to the physician, because of the emotional burden related to the decision (De Haes, 2006). Also, the choice to prolong life can be perceived as 'not a real choice', since appropriate medical alternatives do not exist (De Haes, 2006; Van Leeuwen, Voogt, Visser, Van Der Rijt, & Van Der Heide, 2004). Despite a proved link between SDM and ‘a good death’ and the apparent suitability of SDM in the palliative setting, SDM seemed to be achieved little in advanced / palliative cancer care (Frank, 2009).

1.5 Preferences for participation in decision-making

The most important factor regarding SDM is the need that patients have to actively participate in MDM. Stated otherwise, if patients do not prefer to participate, this is a major barrier (Légaré, Ratté, Gravel & Graham, 2008).

In general, it appears that older patients express a preference for more passive roles in MDM, as compared to younger patients (Deber, Kraetschmer, Urowitz & Sharpe, 2007). Two explanations may account for this. First, older people where raised in times when physicians were traditional power figures, to whom you obeyed (Bastiaens, Van Royen, Rotar Pavlic, Raposo & Baker, 2007; Robinson & Thomson, 2001). This is a cohort effect, rather than an individual age effect. Second, from an age dependent (developmental) perspective, it is suggested that as people age, they want less responsibility in MDM and therefore tend to rely on the expertise of others (Robinson & Thomson, 2001).

Other studies suggest that the desire for participation in MDM is heterogeneous within the group of older patients (Bastiaens et al., 2007; Elkin et al., 2007). However, nowadays elderly patients are better educated and tend to have improved access to information resources. As a result, it is expected that elderly patients will increasingly claim a position in the MDM process (Wymenga et al., 2012). This study hypothesizes that:

There are no differences in preferences for participation in medical decision-making, when comparing ‘old elderly-’ (≥75 years), with ‘young elderly-’ (65-74 years), and ‘middle aged’ (40-64 years) cancer patients.

1.6 Perceived participation in decision-making

In general, the degree of patient participation has increased over time. However, this does not apply to elderly patients, who are least involved in the MDM process (Van Den Brink-Muinen et al., 2006). This does not only raise the question whether elderly patients prefer to be involved in MDM, but also whether they themselves perceive to be involved in the MDM process. This present study examines patients’ perceived degree of participation. It is hypothesized that:

‘Old elderly’(≥75 years) patients less often perceive the decision-making as ‘shared’, as compared to ‘young elderly-’ (65-74 years), and ‘middle aged’ (40-64 years) cancer patients.

1.7 Elements of SDM

In order to assess the process of SDM, rather than solely the outcome, several SDM components are examined on their presence / absence. Patients’ perceived involvement is explored by assessing patient decision-making behaviour, patient-physician information exchange and physicians’ facilitation behaviour towards patient involvement in MDM.

In particular, physicians’ behaviour is important to assess, since a study of Zandbelt, Smets, Oorta, Godfried and De Haes (2006) concluded that physicians display more patient facilitating behaviour as patients are older, indicating that oncologist behavior towards patient centeredness is age dependent. On the contrary, it is known that elderly cancer patients often experience a lock of recognition of their psychosocial needs in communication with their healthcare providers (Alon, 2011). Therefore, the present study assesses the degree of oncologists’ facilitation behaviour and the possible relation with age.

1.8 Concordance

This present study examines whether age influences the degree of concordance in palliative cancer care. Tariman et al. (2010) carried out a systematic review of studies that examine the match between preferred and perceived participation roles (concordance) among patients with cancer. All studies (n=22) showed discrepancies between preferred and actual (or perceived) roles in MDM and the majority of studies found that patients initially preferred more involvement than what actually occurred, across all types of cancer (age was not studied as a possible correlate). Concordance levels of cancer patients in relation to ‘end-of-life decision-making’ also showed that despite preferences to be involved in the MDM process, half of the patients were not (Pardon et al., 2012).

According to Pardon et al. (2012), more insight is needed on why many cancer patients are not involved in MDM, despite their preferences. Likewise, Tariman et al. (2010) stated that research is needed to determine if age influences the actualization of patients preferred role. It is relevant to assess the degree of concordance, since a match between preferred and actual MDM roles is related to patient satisfaction and improved health outcomes (Vogel, Leonhart & Helmes, 2009; Nota, Drossaert, Taal & Van De Laar, 2014). Moreover, a mismatch between the preferred and actual MDM role can result in decision regret (Vogel et al., 2009).

1.9 Age-related aspects towards shared decision-making

Several age-related aspects are included in this study, being Health Related Quality of Life (HR-QoL), patients' feelings of self-efficacy in interaction with physicians, patients' degree of loneliness, and patients' temporal perspective. These aspects are expected to be both indicators of age and associated with patient participation in MDM. These aspects are measured within each age group and plotted against patients' preferred and perceived participation roles as well as concordance in MDM. By doing so, a more substantial meaning is given to the concept of age and potential age-related barriers and facilitators towards patient involvement in MDM are identified. The next sections describe each of the abovementioned age-related aspects and their presumed associations with participation in MDM.

1.9.1 Health-related quality of life

Patients' HR-QoL is assessed, because belonging to an older age group is often perceived as a barrier towards SDM. This relates to factors such as being in poor physical and mental health (Joseph-Williams, Elwyn, & Edwards, 2014; Sainio, Lauri, & Eriksson, 2001). Moreover, studies suggested associations between age-related health decline and preferences for a physician centered style (Levinson, Kao, Kuby & Thisted, 2005).

HR-QoL is stated as the impact of a medical condition (or specific medical interventions) on a person's physical-, psychological- and social well-being (Tang, Aaronson & Forbes, 2004). By assessing patients' physical-, role-, cognitive-, emotional- and social functioning, the relation between the subjective experience of age and participation in MDM is assessed. This study examines if HR-QoL relates to preferred and perceived participation, as well as concordance in MDM. The following hypotheses are established:

1) 'Old elderly' (≥75 years) patients will report lower HR-QoL, as compared to 'young elderly-' (65-74 years), and 'middle aged' (40-64 years) cancer patients.

2) Cancer patients with a lower HR-QoL are less likely to both prefer and perceive SDM than patients with a higher HR-QoL.

1.9.2 *Self-efficacy*

Self-efficacy is defined as the confidence that patients have in their ability to interact with physicians (Ten Klooster et al., 2012). Little attention has been paid to patients‘ feelings of self-efficacy towards interaction with physicians. It is important to gain insight into self-efficacy, since greater feelings of self-efficacy are a powerful independent predictor of patient participation in MDM (Maly, Umezawa, Leake, & Silliman, 2004; Légaré et al., 2008).

Age might influence patients’ self-efficacy, since it is known that older cancer patients often suffer from suboptimal physician-patient communication (Amalraj, Starkweather, Nguyen & Naeim, 2009). Older people on average have more difficulty with the storage and retrieval of information, medical language, and they often experience more medical problems than young people. Furthermore, elderly patients are perceived as a risk group for miscommunication due to cognitive and sensory decline, the lack of social support (Wymenga et al., 2012), as well as lower health literacy (Williams, Davis, Parker & Weiss, 2002; Adelman, Greene & Ory, 2000). As a result, elderly patients can experience lower rates of self-confidence in communicating with the physician and in SDM (Amalraj et al., 2009). Based on these findings, the following hypotheses are established:

1) ‘Old elderly’ (≥75 years) patients have lower feelings of self-efficacy towards interaction with their oncologist, as compared to ‘young elderly-’ (65-74 years), and ‘middle aged’ (40-64 years) cancer patients.

2) Cancer patients with lower feelings of self-efficacy towards interaction with their oncologist are less likely to both prefer and perceive SDM than patients with higher feelings of self-efficacy.

1.9.3 *Loneliness*

The social environment can have a positive impact for patients in terms of mortality, morbidity and self-rated health (Melchior, Berkman, Niedhammer, Chea & Goldberg, 2003). Also, social support helps people to cope with stressful life events and it can enhance physical, psychological and social well-being (Janssen & Pfaff, 2005). Feelings of loneliness therefore, possibly relate to loss of meaning of life. Consequently, patients’ might put less value on quantity of life and are perhaps less likely to participate in MDM, since decisions people make are influenced by the relationships maintained with friends and family (Sueur, Deneubourg & Petit, 2012). The term ‘relational autonomy’ describes that our decisions relate to interpersonal relationships and mutual dependencies (Mackenzie, 2008), which implies that the social environment also influences decisions with regards to health.

More specifically, the presence of companions in general will lead to increased patient involvement and MDM during consultation (Clayman, Roter, Wissow, & Bandeen-Roche 2005). Family members therefore can be key participants in MDM (Maly, Umezawa, Ratliff & Leake, 2006; Lingler, Sherwood, Chrighton, Song & Happ, 2008). Although having close contacts may facilitate active engagement, elderly people often experience a shrinking network and have to deal with a lack of a supportive system (Alon, 2011). This might hinder elderly patient participation in MDM. To assess the influence of the social environment on patients' preferences, perceived participation and concordance in MDM, this study addresses patients' degree of loneliness. The following hypotheses are established:

1) 'Old elderly' (≥75 years) patients experience higher degrees of loneliness, as compared to 'young elderly-' (65-74 years), and 'middle aged' (40-64 years) cancer patients.
2) Cancer patients with higher degrees of loneliness are less likely to both prefer and perceive SDM than patients with lower feelings of loneliness.

1.9.4 Temporal perspective

Temporal perspective is the focus that people have on the past, present and / or future. It is an unconscious process, in which a person's temporal focus strongly influences psychosocial choices, behaviors and consequences (Zimbardo & Boyd, 1999; Boniwell & Zimbardo, 2004). A future oriented perspective is associated with adaptive outcomes, including optimism and having an internal locus of control (Zimbardo & Boyd, 1999). 'Locus of control' (LoC) reflects the individual perception of opportunities to influence the own fate. Persons tend to attribute the control over occurrences either to themselves (internal LoC) or to others and forces outside of themselves (external LoC). Patients with a high internal LoC would prefer more active problem solution strategies, such as seeking information or discussing treatment decisions (Schneider et al., 2006).

Although most adults have a dominant time perspective, these may change over time, indicating a developmental component (Webster, Bohlmeijer & Westerhof, 2014). Younger adults tend to be more future oriented relative to older adults and older adults tend to be more past oriented relative to younger adults (age range varied from 25 till 67 years) (Webster et al., 2014). These age differences in temporal orientation are explained by the fact that older adults, on average, are closer to death and therefore have shorter futures. Although older adults *can* engage in their future, it is known that as people age, they develop shorter time perspectives and become more selective in their goals and activities (Webster et al., 2014). Also, elderly patients are less concerned with being in control and less likely to make major behavior changes (Robinson & Thomson, 2001; O'Blank & Bellizzi, 2008). The following hypotheses are formulated:

1) 'Old elderly' ($\geq$ 75 years) patients have a more past oriented time perspective as compared to 'young elderly-' (65-74 years), and 'middle aged' (40-64 years) cancer patients (higher future oriented time perspective).
2) Cancer patients with a past oriented time perspective are less likely to both prefer and perceive the SDM than patients with a future oriented time perspective.

1.10 Research questions

This study focuses on patients with incurable cancer, treated with palliative chemotherapy.

Main question:

What are the preferences, experiences and correlates towards shared decision-making among ‘old elderly’ cancer patients ($\geq$75 years) and what are similarities and differences as compared to ‘young elderly-’ (65-74 years) and ‘middle aged’ cancer patients (40-64 years)?

Subquestions:

1. To what extent do ‘old elderly’ cancer patients prefer to participate in the decision to use chemotherapy, as compared to ‘young elderly-’ and ‘middle aged’ cancer patients?

2. To what extent do ‘old elderly’ cancer patients perceive they participate in the decision to use chemotherapy, as compared to ‘young elderly-’ and ‘middle aged’ cancer patients?

3. Which elements of shared decision-making are explicitly addressed and which are not? Are there differences among ‘old elderly’ cancer patients as compared to ‘young elderly-’ and ‘middle aged’ cancer patients?

4. To what extent is there concordance between preferences and perceived participation in the decision to use chemotherapy? Are there differences in degrees of concordance when comparing ‘old elderly-’ with ‘young elderly-’ and ‘middle aged’ cancer patients?

5. Is there a relationship between age-related aspects* of cancer patients and preferences for-, as well as perceived participation and concordance in decision-making?
   Age-related barriers and facilitators towards shared decision-making.
   *1) health-related quality of life, 2) self-efficacy, 3) loneliness, 4) temporal perspective

6. Is there a relationship between demographic characteristics* of cancer patients and preferences for-, as well as perceived participation and concordance in decision-making?
   * 1) gender, 2) nationality, 3) marital status, 4) educational level

2. METHODS

2.1 Design

The study design was quantitative. A self-report questionnaire was developed to assess the research questions. The questionnaire was administered once (cross-sectional study) and cancer patients completed the questionnaire after the process of MDM had taken place (retrospective).

Approval for this study was obtained by the ‘Commissie Ethiek van de faculteit gedragswetenschappen’ of the University Twente, as well as the Medical Ethical Committee of Twente (METC/14333.KOR). All participants gave informed consent before participating in the study.

2.2 Participants & procedure

This study was conducted within the Medical Spectrum Twente (MST), located in Enschede and Oldenzaal, the Netherlands. The department of internal medicine, hematology and oncology was closely involved. During a period of ten weeks (february, march, and first half of april, 2015), all patients facing metastatic cancer who met the inclusion criteria were approach personally by the researcher to participate in this study (consecutive sampling). Patients who decided not to enter palliative chemotherapy were not included. The consecutive sampling technique is the better choice of the non-probability sampling techniques because it can result in a good representation of the overall population, during a period of time (Tariman et al., 2010).

Participants had to meet the following inclusion criteria: 1) aged 40 years or older, 2) diagnosed with metastatic cancer and, 3) receiving (life prolonging) chemotherapy at the MST. Participants were excluded in case of: severe cognitive impairment and inadequate understanding of the Dutch language. A total of 84 patients were approached to participate in this study, 77 patients granted consent. Seven patients declined due to general disinterest related to the severity of the disease. This equates a response rate of 91.7%.

Table 1 provides the distribution of participants’ demographic characteristics. When observing age, it can be stated that the mean age of the three age groups are relatively close to each other. Gender is roughly equally distributed between males and females. With respect to the demographics nationality, marital status and education level, participants were predominantly Dutch, cohabiting and lower educated. With only one ‘non-Dutch’ participant, the demographic nationality will be excluded in the results part.

Table 1: Demographics (n=77)

Characteristic	**mean**	**(range)**	**SD**	**n**	**%**
Age (in years)	67.3	(43-91)	10.5		
Age group (in years)					
40-64	55.8			28	36.4
65-74	69.8			25	32.5
≥ 75	78.3			24	31.2
Gender					
Male				41	53.2
Female				36	46.8
Nationality					
Dutch				76	98.7
Non-Dutch				1	1.3
Marital status					
Single				20	26.0
Cohabiting				57	74.0
Education level					
High				13	16.9
Medium				15	19.5
Low				48	62.3
Most involved physician towards decision for chemotherapy					
Internist/oncologist/hematologist				75	97.4
Other				2	2.6

More specifically, the oncologist or the nurse practitioner assessed whether patients did meet inclusion- or exclusion criteria, using the database (X-Care) of the MST. Patients were recruited in the outpatient department, the outclinic and on the clinical ward. Patients were approached while visiting the MST for a medical appointment (chemotherapy and / or consultation with oncologist).

After a short introduction, patients were handed the questionnaire (Appendix A) and the information brochure with informed consent form (Appendix B). The questionnaire was administered in a physician's office. Several patients who visited the MST specifically for chemotherapy at the outclinic preferred to complete the questionnaire while undergoing chemotherapy. This was approved by the researcher, given the fact that chemotherapy was also administered in a quiet, private room. In most cases, patients were accompanied by a family member. When patients appreciated it, family members were welcome to be present while the questionnaire was administered. However, it was explicitly requested not to interfere with the content of the questionnaire.

2.3 Instruments

Several validated instruments were used in the questionnaire. Each will be described in the following sections. The questionnaire was written in Dutch, since the study was carried out in the Netherlands. Most of the scales were originally written in English. When Dutch versions of the scales were absent, original instruments were translated from English to Dutch using a forward / direct translation procedure (McKay et al., 1996). This was done by three persons (CB, CD, and CGK), who master both the English language and the target language (Dutch) very well. Wording of the questions was discussed until agreement was reached. Other adaptations were made in the way that ‘my doctor’ was changed into ‘my oncologist’ and statements were specified towards the decision about whether to enter into palliative chemotherapy. Scale statistics of each subscale are mentioned in the corresponding paragraphs. An overview of the Cronbach’s alphas of this study can be found in Table 2.

2.3.1 Demographics

The following demographics were included: age, gender, nationality, marital status and educational level. The variables gender, nationality and marital status were answered using a binary response format (man/woman; Dutch/non-Dutch; single/cohabiting). For the variable age, an open question was used. This enabled drawing conclusions about the minimum, maximum and average age of the participants. Prior to the data-analysis, patients’ age was recomputed into the aforementioned ‘age-groups’. The variable educational level was recomputed into low, medium, and high.

2.3.2 EORTC QLQ-C30 (version 3.0)

The EORTC QLQ-C30 was used to assess patients’ health related quality of life, because it is a frequently used and validated, cancer specific questionnaire (Aaronson et al., 1993).

The QLQ-C30 incorporates five functional scales: physical functioning (Cronbach’s α = 0.79), role functioning (Cronbach’s α = 0.81), cognitive functioning (Cronbach’s α = 0.60), emotional functioning (Cronbach’s α = 0.83) and social functioning (Cronbach’s α = 0.73). Three symptom scales measure the degree of pain (Cronbach’s α = 0.89), fatigue (Cronbach’s α = 0.86) and nausea and vomiting (Cronbach’s α = 0.78). Several single-item measure insomnia, constipation and financial difficulties. The instrument ends with two items related to global health and quality-of-life (Cronbach’s α = 0.89).

This present study used the Dutch version of the EORTC QLQ-C30: version 3.0 (EORTC, 1995). An example item of the physical functioning scale is *‘Do you need help with eating, dressing, washing yourself or using the toilet?’*. All scales could be answered with a four point Likert scale, ranging from ‘not at all’, to ‘very much’. Participants could rate their global health and quality of life, with a seven point Likert scale, ranging from ‘very bad’ to ‘excellent’.

Scores were linearly transformed to a range from 0 to 100. Higher scores on functional scales indicate better levels of functioning. Also, a higher score on quality of life represents a higher quality of life. Higher scores on symptom scales indicate more medical symptoms.

2.3.3 Control Preferences Scale

The Control Preferences Scale (CPS) was administered to determine patients’ participation preferences in MDM. The CPS is the most commonly used instrument for this purpose (Tariman et al., 2010; Hubbard, Kidd & Donaghy, 2008; Degner, Sloan & Venkatesh, 1997). The CPS was developed specifically for research with people facing life threatening diseases. It is stated as a clinically relevant, easy to use, valid and reliable measure instrument (Degner et al., 1997).

‘Control Preference’ is defined as *‘the degree of control an individual wants to assume when decisions are being made about medical treatment’* (Degner et al., 1997, p 21). The statements in the present study were displayed with images (Solari et al., 2013), in order to support comprehension of the participants (see figure 2). Participants were asked to choose one out of five of the following statements:

A: I prefer that I make the final decision about whether to enter into chemotherapy.

B: I prefer that I make the final decision about whether to enter into chemotherapy, after seriously considering my oncologists’ opinion.

C: I prefer that my oncologist and I share the responsibility in deciding whether or not to enter into chemotherapy.

D: I prefer that my oncologist makes the final decision about whether to enter into chemotherapy, but seriously considers my opinion.

E: I prefer that my oncologist makes the final decision about whether to enter into chemotherapy.

These five response options were recoded into three categories, consistent with Charles’s model of MDM styles: active / patient centered (statements A and B), passive / physician centered (statements D and E) and shared (statement C) (Charles, Gafni, & Whelan, 1999).

In order to assess patients’ perceived participation in MDM, a modification of the CPS was used. This so called ‘Patient Perception Scale’ (PPS) was used in a study of Janz et al. (2004). The PPS differs from the CPS in the way that ‘prefer’ was replaced for ‘made’. Figure

2 shows one adapted statement from both the CPS, as well as the PPS, used in this present study.


Ik geef er de voorkeur aan dat mijn oncoloog en ik de verantwoordelijkheid delen bij de beslissing over het wel of niet aangaan van een chemokuur.

Mijn oncoloog en ik hebben de verantwoordelijkheid gedeeld over de beslissing van het wel of niet aangaan van een chemokuur.

Figure 1: Preferred participation versus perceived participation

Patients' degree of concordance was computed by subtracting patients' participation preferences from their perceived participation roles.

2.3.4 Perceived Involvement in Care Scale

The 'Perceived Involvement in Care Scale' (PICS) (Lerman et al., 1990) was used in order to measure the degree to which patients feel involved in MDM. The scale constitutes of 13 statements, which relate to the following subscales: 'doctor facilitation' (Cronbach's α = 0.73), 'patient physician information exchange' (Cronbach's α = 0.60) and 'patient decision-making' (Cronbach's α = 0.54). Example item are: '*My oncologist asked me whether I agree with his / her proposal for whether or not to enter into chemotherapy*' (doctor facilitation scale), *'I asked my oncologist to explain to me the details of chemotherapy'* (patient physician information exchange scale) and *'I gave my opinion about whether or not to enter into chemotherapy'* (patient decision-making scale).

Responses were given on a two-points agree/disagree scale. 'Disagree' gives 0 points and 'agree' gives 1 point. Higher scores reflect a greater degree of perceived patient activity and involvement.

2.3.5 Decisional conflict scale – Information subscale

The information subscale of the decision conflict scale (O'Connor, 1993) was used to assess whether patients were given information on various treatment options and their potential risks and benefits. This present study was able to demonstrate a good internal consistency (Cronbach's α = 0.89). The information subscale consists of three items: *'I was aware of all treatment options'*, *'I was aware of the benefits of all treatment options'* and *'I was aware of the risks and side effects of all treatment options'*.

Answers were given on a 5 point Likert scale, ranging from strongly agree (0 points) to strongly disagree (4 points). Scores were computed by summing up the scores of the three items. This score was divided by three and then multiplied by 25. Scores ranged from 0 (feels extremely informed) to 100 (feels extremely uninformed).

2.3.6 Perceived Efficacy in Patient-Physician interactions

In order to measure patients' self-efficacy in their ability to interact with their oncologist, the Perceived Efficacy in Patient-Physician Interactions (PEPPI) was applied (Maly, Frank, Marshall, DiMatteo & Reuben, 1998). The PEPPI was developed to measure feelings of self-efficacy in older patients, with regards to obtaining medical information, as well as getting attention from their physician towards their main health concerns (Maly et al., 1998).

Originally, the PEPPI contained 10 items. This study used the Dutch and shortened, 5 item version: PEPPI-5 (Ten Klooster et al., 2012) and demonstrated a high internal consistency (Cronbach's ɑ = 0.94). An example item from the questionnaire is: *'How confident are you that you know which questions to ask your oncologist?'*. Five answer possibilities were given, ranging from 'not at all confident' to 'very confident'. Scores of the PEPPI-5 were summed up and ranged from 5 to 25. Higher scores represented higher perceived self-efficacy in patient-oncologist interactions.

2.3.7 Loneliness scale

In order to assess feelings of loneliness, the loneliness scale of De Jong Gierveld (2008) was used. The original, 11-item scale is proven a valid and reliable measuring instrument (De Jong Gierveld & Van Tilburg, 2008). This present study has used the shortened (six item) version. The instrument distinguishes between emotional- (Cronbach's ɑ = 0.82) and social loneliness (Cronbach's ɑ = 0.86). An example item is: *'There are enough people with whom I feel closely connected'*. Answers could be rated on a 5-point Likert scale, ranging from 'certainly' to 'certainly not'.

In the 'emotional' subscale, participants obtained 1 point for the answer 'definitely yes', 'yes', 'more or less'. The 'social' subscale gives 1 point when answered with 'more or less', 'no', 'certainly not'. The higher the number of points (up to 6), the greater is the indication of loneliness.

2.3.8 Temporal Focus Scale

The Temporal Focus Scale (TFS) was used to assess patients' tendency to think about the past, present or future (Shipp, Edwards & Schurer-Lambert, 2009). The TFS consists of 12 items. Four items measure a tendency to think about the past (Cronbach's ɑ = 0.79). For example *'I reflect on what has happened in my life'*. Also four items focus on the present *'I live my life in the present'* (Cronbach's ɑ = 0.79) and another four items relate to having a future oriented focus (Cronbach's ɑ = 0.85). For example: *'I imagine what tomorrow will bring me'*.

Answers were rated on a 7-point Likert scale, describing the frequency to which the respondent thought about the time frame indicated by the item (1 = never; 3 = sometimes; 5 = frequently; 7 = constantly). For each time frame a sub score was computed by summing up the item scores. Higher scores are indicative of a higher focus on the given time frame.

2.4 Data analysis

Data analysis was performed using SPSS statistics version 22. Distributions of preferred and perceived participation, as well as concordance related to both age groups and demographics, were described by means of crosstabs. To test whether significant differences existed, Pearson Chi-square tests were performed.

Elements of SDM as well as relationships between both age groups and MDM and HR-QoL, self-efficacy, loneliness and temporal perspective were univariate compared across age groups, describing their means and standard deviations.

Histograms were used to check on normal distributions between nominal/ordinal variables and their relationships with continuous variables. This revealed skewed distributions. Therefore, non-parametric Kruskal-Wallis tests were performed to test on significant differences.

Table 2: Scale statistics

Scale / subscale	**Cronbach's α**	**# items**	**min**	**max**	**range**
EORTC-QLQ-C30 (3)					
Global health status / QoL	0.89	2	1	7	2-14
Functional scales					
Physical functioning	0.79	5	1	4	5-20
Role functioning	0.81	2	1	4	2-8
Emotional functioning	0.83	4	1	4	4-16
Cognitive functioning	0.60	2	1	4	2-8
Social functioning	0.73	2	1	4	2-8
Symptom scales					
Fatigue	0.86	3	1	4	3-12
Nausea and vomiting	0.78	2	1	4	2-8
Pain	0.89	2	1	4	2-8
Perceived Involvement in Care Scale					
Doctor facilitation	0.73	5	0	1	0-5
Patient information	0.60	4	0	1	0-4
Patient decision-making	0.54	4	0	1	0-4
Decisional Conflict scale					
Information subscale	0.89	3	0	4	0-12
PEPPI-5	0.94	5	1	5	5-25
Loneliness scale					
Emotional loneliness	0.82	3	1	5	3-15
Social loneliness	0.86	3	1	5	3-15
Temporal focus scale					
Past orientation	0.79	4	1	7	4-28
Present orientation	0.79	4	1	7	4-28
Future orientation	0.85	4	1	7	4-28

3. RESULTS

3.1 Preferences for participation

In general, a majority of patients preferred a patient centered MDM style, meaning that they alone, or with consideration of the oncologists' opinion, would like to make the decision (table 3). SDM was preferred second. A minority, but almost 1 out of 5 patients preferred to leave the decision whether or not to enter into palliative chemotherapy to the oncologist (physician centered).

The distribution of patient preferences across the three age groups revealed that the majority of the 'middle aged' cancer patients (40-64 years) preferred to share the decision, whereas young elderly-' (65-74 years), as well as 'old elderly' patients (≥ 75 years) preferred a patient centered style. However, no association between preferences for involvement and age groups was found.

Table 3: Crosstab and Pearson X^2 for age groups in relation to preferred participation (n=77)

	Age groups						**Total**		**X^2**	**p**
Preferred participation	**40-64** *n = 28*		**65-74** *n = 25*		**≥ 75** *n = 24*		*n = 77*			
	n	(%)	n	(%)	n	(%)	n	(%)	1.32	0.86
Physician centered	6	(21.4)	4	(16.0)	4	(16.7)	14	(18.2)		
Shared	12	(42.9)	9	(36.0)	8	(33.3)	29	(37.7)		
Patient centered	10	(35.7)	12	(48.0)	12	(50.0)	34	(44.2)		

3.2 Perceived participation

In general, a large majority of the patients perceived the MDM as patient centered (table 4). Contradictory to preferences for participation, SDM was least often perceived. This difference is attributed to the increased number of perceived physician centered MDM, which is at the expense of lower levels of SDM.

Perceived participation levels across the age groups showed that within all age groups, a majority perceived the MDM as patient centered, indicating no association between perceived participation and age groups.

Table 4: Crosstab and Pearson X^2 for age groups in relation to perceived participation (n=77)

	Age groups						**Total**		**X^2**	**p**
Perceived participation	**40-64**		**65-74**		**≥ 75**					
	n = 28		*n = 25*		*n = 24*		*n = 77*			
	n	(%)	n	(%)	n	(%)	n	(%)	0.72	0.95
Physician centered	9	(32.1)	8	(32.0)	6	(25.0)	23	(39.9)		
Shared	8	(28.6)	6	(24.0)	8	(33.3)	22	(28.6)		
Patient centered	11	(39.3)	11	(44.0)	10	(41.7)	32	(41.6)		

3.3 Elements of SDM

3.3.1 Doctor facilitation

In general, oncologists gave patients good explanations about symptoms and chemotherapy (table 5). Also, a large majority of patients perceived that their oncologist asked whether they agreed with the proposal for chemotherapy. However, a minority of patients perceived that their oncologist asked patients' opinion towards their perceived cause of symptoms. Furthermore, patients in general perceived little encouragement by their oncologist to talk about their worries.

A closer examination on doctor facilitation behavior across age groups revealed a significant association. Oncologists (as perceived by patients) encouraged 'old elderly' patients (≥ 75 years) significantly less often to talk about worries, as compared to 'middle aged' patients (40-64 years) ($X^2 = 6.60$: $p = 0.04$). None of the other doctor facilitation elements yielded significant associations with age groups.

3.3.2 Patient information

In general, a majority of patients asked their oncologist 1) to explain the chemotherapy in detail, 2) advice for their symptoms and 3) many patients told their oncologist about their symptoms (Table 5).

When comparing scores across age groups, a nearly significant association ($X^2 = 5.83$: $p = 0.05$) showed that 'middle aged' patients (40-64 years) asked their oncologist more often a lot of questions about their symptoms, as compared to 'young elderly' (65-74 years) patients. A trend ($X^2 = 4.99$: $p = 0.08$), shows that 'old elderly' patients (≥ 75 years) asked their oncologist less often to explain the chemotherapy in detail to them, as compared to 'middle aged' patients (40-64 years). Also, patients tent to ask their oncologist less often advice for symptoms as patients are older ($X^2 = 3.88$: $p = 0.14$).

3.3.3 Patient decision-making

Overall scores of patient DM behavior were relatively low (table 5). A minority of patients 1) proposed or insisted on a certain kind of test/treatment and 2) expressed doubts about the chemotherapy their oncologist recommended. A majority of patients did give their opinion about whether or not to enter into palliative chemotherapy. Associations between patient DM behavior and age groups were not found.

3.3.4 Information

In general, patients perceived that information of possible treatment options and their benefits and risks was provided (table 5). No differences between information provision across the age groups was found. Means, standard deviations and p- values of the subscales can be found in Appendix C, table 6a + 6b.

N.B.: Continuous / scale variables are described by means and standard deviations. To test on significant differences, non-parametric (Kruskal-Wallis) tests were performed (non-normally distributed data). Therefore, p-values are shown separately in the text and are not shown in the tables.

Table 5: Elements of SDM across age groups- percentages and standard deviations (n=77)

Subscale	**Age groups**						**Total**	
	40-64		**65-74**		**≥ 75**			
	n = 28		*n = 25*		*n = 24*		*n = 77*	
	%	(SD)	%	(SD)	%	(SD)	%	(SD)
Doctor facilitation								
My oncologist:								
… asked me whether I agree with his / her proposal, whether or not to enter into chemotherapy.	93	(0.26)	88	(0.33)	83	(0.38)	88	(0.32)
… has encouraged me to talk about my worries.	61	(0.50)	44	(0.51)	25	(0.44)	44	(0.50)
… has encouraged me to give my opinion about the chemotherapy.	68	(0.48)	64	(0.49)	67	(0.48)	66	(0.48)
… gave me a good explanation about my symptoms and chemotherapy treatment.	96	(0.19)	100	(0.00)	92	(0.28)	96	(0.20)
… asked me what I believe is causing my symptoms.	61	(0.50)	44	(0.51)	38	(0.50)	48	(0.50)

Subscale	**Age groups**						**Total**	
	40-64		**65-74**		**≥ 75**			
	n = 28		*n = 25*		*n = 24*		*n = 77*	
	%	(SD)	%	(SD)	%	(SD)	%	(SD)
Patient information								
I have:								
…asked my oncologist to explain to me the chemotherapy in detail.	81	(0.40)	76	(0.44)	54	(0.51)	71	(0.46)
…asked my oncologist advice for my symptoms.	86	(0.36)	68	(0.48)	63	(0.50)	73	(0.45)
…told extensively about my symptoms.	86	(0.36)	80	(0.41)	79	(0.42)	82	(0.39)
…asked my oncologist a lot of questions about my symptoms.	75	(0.44)	44	(0.51)	50	(0.51)	57	(0.50)
Patient decision-making								
I have:								
… proposed a certain kind of treatment to my oncologist.	18	(0.39)	8	(0.28)	17	(0.38)	14	(0.35)
… insisted on a certain kind of test or treatment.	14	(0.36)	16	(0.37)	17	(0.38)	16	(0.37)
… given my opinion about whether or not to enter chemotherapy.	81	(0.40)	76	(0.44)	67	(0.48)	75	(0.44)
… expressed doubts about the chemotherapy my oncologist recommended.	15	(0.36)	8	(0.28)	4	(0.20)	9	(0.29)
Information	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
I was aware of: (0-4)								
… all treatment options.	1.04	(0.79)	1.40	(0.87)	1.46	(1.06)	1.29	(0.92)
… the benefits of all treatment options.	1.29	(0.94)	1.40	(0.91)	1.29	(0.91)	1.32	(0.91)
… the risks and side effects of all treatment options.	0.93	(0.72)	1.32	(0.80)	1.33	(0.96)	1.18	(0.84)

Higher percentages on the doctor facilitation, patient info and patient decision-making scale reflect higher doctor facilitation / patient involvement. Means of the information subscale range from 0 – 4: 0 points reflecting highest awareness and 4 points reflecting lowest awareness.

N.B. for the doctor facilitation, patient information and patient decision-making scale: Percentages can also be interpreted as means, since scores were either ranked with 1 point (yes) or 0 points (no). Therefore, standard deviations are also displayed, based on the mean scores, which is the same in this case as a percentage.

3.4 Concordance

Overall, almost three-quarter of the patients perceived a match between their preferred- and perceived participation role (Table 7). From the patients who perceived a mismatch, the majority experienced less involvement than preferred. Nearly 20% of patients was less involved than they initially preferred in the MDM process.

Associations between the degree of concordance and age groups were not found.

Table 7: Crosstab and Pearson X^2 for concordance across age groups (n=77)

Concordance	**Age groups**						**Total**		**X^2**	**p**
	40-64		**65-74**		**≥ 75**					
	n = 28		*n = 25*		*n = 24*		*n = 77*			
	n	(%)	n	(%)	n	(%)	n	(%)		
									1.81	0.77
Less than preferred	5	(17.9)	5	(20.0)	4	(16.7)	14	(18.2)		
Concordance	19	(67.9)	18	(72.0)	19	(79.2)	56	(72.7)		
More than preferred	4	(14.3)	2	(8.0)	1	(4.2)	7	(9.1)		

3.5 Age-related aspects

To test whether the age-related aspects HR-QoL, self-efficacy in communication with the oncologist, loneliness, and temporal perspective influence preferred- and perceived participation as well as levels of concordance, a two-step approach was conducted. First, relationships between age-related aspects and age groups will be described, followed by the relationship with patients' preferences, perceived participation and concordance in MDM.

3.5.1 Relationship between age and age-related aspects (Appendix C, table 8+9)

Although both physical and cognitive functioning decline slightly as patients belong to an older age group, the present study was not able to demonstrate a relationship between HR-QoL and age groups.

While patients' feelings of self-efficacy in communicating with the oncologist show that self-efficacy gradually declines a little as age increases, associations between patients' feelings of self-efficacy in communication with their oncologist did not relate to age groups in this sample (p =0.49).

Associations between feelings of loneliness and age groups were neither found in the present study.

The temporal focus scale showed a trend ($X^2 = 3.66$: p = 0.16), where 'old elderly' patients (≥ 75 years) do have the highest focus on the past, as compared to both 'young elderly-' (65-74 years) and middle aged patients (40-64 years). Nonetheless, significant associations between patients' temporal focus and age groups were not found in this study.

3.5.2 Relationship between age-related aspects and decision-making

N.B. HR-Qol: see Appendix C, table 10 + 11. Self-efficacy, loneliness and temporal focus: table 12 (p.26) + table 13 (Appendix C).

None of the HR-QoL subscales demonstrated meaningful associations in relation to both preferred- and perceived participation in MDM, as well as concordance, indicating that HR-QoL was not associated with MDM.

However, increased levels of self-efficacy were significantly associated ($X^2 = 6.62$: $p = 0.04$) with perceived SDM, whereas decreased levels of self-efficacy related towards a perceived physician centered MDM style (table 12). Associations between self-efficacy and preferences for participation, as well as concordance were not found in the present study

The loneliness scale was not able to demonstrate differences in relation to preferred- and perceived participation in MDM, as well as concordance, indicating that feelings of loneliness do not relate towards participation in MDM.

Finally, patients' temporal focus did neither show associations with patients' preferred- and perceived participation in MDM, as well as concordance. This points to the finding that participation in MDM does not relate towards a past, present or future time perspective.

Table 12: Means and standard deviations for self-efficacy, loneliness and temporal perspective; split by preferred and perceived participation in decision-making (n=77)

Variable Subscale	**Preferred** **Physician centered**	 **Shared**	 **Patient centered**	**Perceived** **Physician centered**	 **Shared**	 **Patient centered**
	n = 14	*n = 29*	*n = 34*	*n = 23*	*n = 22*	*n =32*
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1: Self-efficacy in communication oncologist	17.8 (4.7)	20.3 (3.4)	20.6 (3.6)	18.6 (4.1)	21.5 (2.6)	19.9 (4.0)
2: Loneliness (total)	1.0 (1.4)	1.4 (2.0)	0.7 (1.1)	0.9 (1.6)	1.1 (1.7)	1.0 (1.5)
- Emotional loneliness	0.6 (1.3)	0.9 (1.3)	0.4 (0.6)	0.5 (1.0)	0.8 (1.2)	0.6 (1.0)
- Social loneliness	0.4 (0.9)	0.5 (0.9)	0.3 (0.7)	0.4 (0.9)	0.3 (0.6)	0.4 (0.8)
3: Temporal focus						
- Past focus	12.6 (4.9)	14.4 (3.6)	13.9 (3.4)	12.8 (4.1)	14.6 (3.5)	14.2 (3.8)
- Current focus	18.3 (5.4)	17.7 (4.8)	18.3 (5.0)	18.2 (4.1)	17.3 (5.0)	18.5 (5.5)
- Future focus	15.9 (5.8)	15.0 (4.3)	16.4 (5.8)	16.9 (5.8)	14.4 (4.0)	15.9 (5.5)

- *Scores on self-efficacy range between 5 and 25, with higher scores representing higher self-efficacy in communicating with the oncologist.*
- *Scores on loneliness (total) range between 0 and 6. Higher scores represent higher levels of loneliness.*
- *Scores of each subscale of the temporal focus scale range between 4 and 28. Higher scores indicate a higher focus on the given time frame.*

3.6 Demographics and decision-making

The last sections describe the demographics gender, marital status and educational level in relation to preferred- and perceived participation in MDM, as well as concordance.

3.6.1 Preferences for participation and demographics

No association between preferences for participation and demographics were found in the present study (table 14). Nonetheless, the main findings will be shortly described.

When observing preferences for participation in DM and gender, it is noticed that the majority of the males preferred a patient centered DM style, whereas females preferred to share the decision. As stated, this finding was non-significant ($X^2 = 5.08$: p = 0.08).

With regards to marital status, the majority of the single patients preferred a patient centered approach. Among patients who live together, preferences for participation were equally divided between patient centeredness and SDM. However, the value of p = 0.52

indicated no association between marital status and preferences for participation in MDM.

A majority of both low, medium and high educated patients preferred a patient centered DM style. Therefore, educational level was not associated with preferences for participation in the present study. However, a trend became prevalent, showing that ‘low’ educated patients more often preferred a physician centered style- and least often a patient centered style, as compared to ‘medium’ and ‘high’ educated patients ($X^2 = 6.58$: $p = 0.14$).

3.6.2 Perceived participation and demographics

Significant differences between gender and perceived participation in MDM were found (table 14). The majority of males perceived the MDM as patient centered, whereas females labeled it most often as ‘shared’, indicating meaningful associations between gender and perceived participation in MDM ($X^2 = 8.79$: $p = 0.01$).

Associations between the demographic marital status and perceived participation roles in MDM were not found in the present study ($p = 0.34$).

Neither were associations found between educational level and patients’ perceived participation in MDM. Nevertheless, a trend was observed, since ‘low’ educated patients perceived the MDM most often as physician centered, whereas both ‘medium’ and ‘high’ educated patients perceived it most often as patient centered ($X^2 = 8.02$: $p = 0.09$).

3.6.3 Concordance and demographics

No associations between patients’ level of concordance and the demographics gender ($p = 0.35$), marital status ($p = 0.75$) and educational level ($p = 0.55$) were found (Appendix C, table 15). However non-significant, it can be stated that males more often perceived a ‘match’ between preferred and perceived roles in MDM, as compared to females. Moreover, females were more often less involved than preferred in MDM, as compared to their male counterparts.

Table 14: Crosstab and Pearson X^2 for preferred-, perceived participation and demographics (n=77)

	Preferred				**Perceived**			
	Physician	**Shared**	**Patient**	**X^2 p**	**Physician**	**Shared**	**Patient**	**X^2 p**
	n = 14	*n = 29*	*n = 34*		*n = 23*	*n = 22*	*n =32*	
Demographics	n (%)	n (%)	n (%)		n (%)	n (%)	n (%)	
Gender				5.08 0.08				8.79 **0.01**
Male	6 (14.6)	12 (29.3)	23 (56.1)		11 (26.8)	7 (17.1)	23 (56.1)	
Female	8 (22.2)	17 (47.2)	11 (30.6)		12 (33.3)	15 (41.7)	9 (25.0)	
Marital status				1.29 0.52				2.13 0.34
Single	3 (15.0)	6 (30.0)	11 (55.0)		4 (20.0)	8 (40.0)	8 (40.0)	
Cohabit	11 (19.3)	23 (40.4)	23 (40.4)		19 (33.3)	14 (24.6)	24 (42.1)	
Education level				6.85 0.14				8.02 0.09
Low	13 (27.1)	17 (35.4)	18 (37.5)		19 (39.6)	13 (27.1)	16 (33.3)	
Medium	1 (6.7)	6 (40.0)	8 (53.3)		4 (26.7)	4 (26.7)	7 (46.7)	
High	0 (0.0)	6 (46.2)	7 (53.8)		0 (0.0)	5 (38.5)	8 (61.5)	

Significant p values are bold

4. DISCUSSION

4.1 Results in context of literature

4.1.1 Preferences for participation

In general, a majority of patients preferred to be actively involved in MDM (patient centered). SDM was preferred second and almost 1 out of 5 patients did not want to participate in MDM. Preferences for participation did not differ across age groups, which was in line with the initial hypothesis.

For a long time the idea was prevalent that older patients prefer passive participation roles (Deber et al., 2007). More recent studies indicated that older patients might desire involvement in MDM to the same extent as younger patients (Doherty & Doherty, 2005). Although elderly patients can express preferences for SDM, most studies report highly heterogeneous preferences among elderly patients (Bastiaens et al., 2007; Elkin et al., 2007). The results of this present study are partly consistent with this, since patients preferences for involvement in MDM did not differ across age groups, indicating that age is not related to patients preferences for involvement in MDM. However, the finding that half of the 'old elderly' patients (≥ 75 years) preferred an active, patient centered role in MDM, indicates relatively homogeneous, instead of heterogeneous preferences.

These non-existing age differences, as well as the high degree of preferences for active participation might be explained by the palliative setting of the cancer. Choices in this stage of cancer are associated with clinical uncertainty regarding the best treatment and decisions have a substantial impact on health outcomes. In these cases, preferences to participate in MDM may be stronger (Whitney, 2003). Moreover, the following quote might prove a better explanation:

> *'How can any of us exercise control over what is happening at the time of death? Is this not stretching a desire for autonomy beyond the limits of possibility?'* (Lloyd, 2004, p 244)

A more general explanation for this result relates to the finding that elderly patients nowadays are better educated and have access to more information resources than decades ago (Wymenga et al., 2012). Consequently, elderly patients may feel able to participate in MDM, displaying heightened preferences for SDM or patient centered roles.

Overall preferences for patient centeredness implicates that oncologists should not underestimate active participation preferences of especially elderly cancer patients, in a palliative setting. Hence, attention must be paid to avoid a traditional paternalistic approach. However, 1 out of 5 patients did not prefer to participate in MDM. This study stresses the importance for oncologists to ask patients' preferences for participation in advance.

4.1.2 Perceived participation

A majority of patients within all age groups perceived the MDM as patient centered. Also, levels of SDM were comparable across the age groups, indicating that age does not influence patients' perceived participation in MDM. This finding was contradictory to the hypothesis, which stated that differences would be found between the age groups.

Literature states that although general degrees of patient participation increased over time, elderly patients are least involved in the MDM process (Van Den Brink-Muinen et al., 2006). The results of the present study contradicts this, which can be explained by the palliative setting, since patients with metastatic cancers are often more experienced and familiar with chemotherapy, oncologists and the MDM process. These 'expert patients' may be more likely to actively participate (Grunfeld et al., 2006; Brom et al., 2014).

This implicates that patients not only can prefer to participate in MDM, but also might feel competent to *actual* participate in MDM. In those cases, the use of a physician centered, paternalistic decision-making style should be avoided. Therefore, if patients prefer sharing decisions, SDM seems feasible to achieve in palliative cancer care, regardless of patients' age.

4.1.3 Elements of SDM

In general, oncologists did facilitate patient involvement by giving good explanations about the upcoming chemotherapy and asking whether patients' agreed with the proposal for palliative chemotherapy. This indicates that oncologist facilitating behavior is age-independent, which contradicts the finding of Zandbelt et al. (2006) who concluded that physicians display more patient facilitating behaviour as patients are older.

However, 'old elderly' ($\leq$ 75 years) patients were significantly less encouraged to talk about worries as compared to 'middle aged' (40-64 years) cancer patients. These results suggest that oncologists do involve elderly patients in the MDM process, by asking for their opinion towards palliative chemotherapy, but provide them with less support.

Literature underlines the same finding, in the way that elderly cancer patients often experience a lack of recognition of psychosocial needs. Hence, psychological distress with regards to difficulties in adjustment, demoralization and fears from dependency and dying remains undetected (Alon, 2011). Younger patients tent to receive priority, assuming that their psychological needs are more urgent and due thoughts that cancer is an unavoidable part of aging, and therefore elderly cancer patients should experience no stress.

Consequently, the present study advocates for heightened awareness and better detection of elderly patients' worries and psychosocial needs by oncologists.

4.1.4 Concordance

Almost 75% of the participants perceived a match between preferred and perceived participation roles. Relationships with age-groups were not found, thus concordance was age-independent. Compared with other studies, this study was able to demonstrate relatively high levels of concordance. For example, the study of Janz et al. (2004) demonstrated a concordance level of 42% and Wallberg et al. (2000) reported matches in 72% of the cases.

Nevertheless, this study showed that the majority of patients who reported a mismatch, was less involved than preferred. This result is consistent with the finding of Tariman et al. (2010), whose systematic review of concordance levels in cancer patients spoke of a pervasive mismatch, since patients wanted more participation than what actually occurred. The finding is also in line with the study of Pardon et al. (2012), which showed that despite preferences, half of the patients in palliative cancer care were not involved in MDM. This implies that oncologists should not automatically assume that patients' preferences for participation in MDM are properly assessed. Predicting patients' role preferences might lead to miscalculations and should be avoided (Tariman et al., 2010).

As a result, the present study advocates for open communication between oncologists and patients, that should allow patients to achieve their preferred level of participation in MDM. Moreover, since patients' role preferences vary and may change shift towards more active participation in the later phases of treatment (Brom et al., 2014), individual assessment should be carried out during the entire course of treatment planning, particularly each time a critical treatment decision is about to be made (Tariman et al., 2010).

4.1.5 Age-related aspects and decision-making

Neither of the variables HR-QoL, self-efficacy, loneliness and temporal perspective was able to demonstrate a (significant) association with age. Several explanations may account for this. Regarding HR-QoL it can be stated that undergoing chemotherapy for palliative purposes, may account for different effects for different patients. When administering palliative chemotherapy, important objectives are to limit disease-related symptoms, slowing of disease progression and prolonging life (Wymenga et al., 2012). However, patients perceived HR-

QoL depends largely on the type and severity of the given chemotherapy and the interaction with individual patient characteristics.

Patients' feelings of self-efficacy in communication with their oncologist was not associated with age. In general, patients were highly confident of their ability to effectively communicate with their oncologist. Literature states that patients with advanced age might suffer from suboptimal physician-patient communication, due to possible deficiencies in their ability to understand, recall and act upon information concerning treatment risk and benefit (Amalraj et al., 2009). Consequently, 'old elderly' patients were expected to face limited feelings of self-efficacy. The finding that especially older patients are likely to be accompanied during treatment consultations might prove an explanation. Family members are key participants in MDM and can play important roles in communication with physicians (Amalraj et al., 2009; Clayman et al., 2005; Lingler et al., 2008; Shields et al., 2005). Especially patients with lower health-literacy are more likely to be influenced by their companion (Amalraj et al., 2009). Therefore, bias may have occurred, since elderly patients might have responded with their involved family in mind. It is plausible that actual self-efficacy feelings of elderly patients are lower, when not supported by significant others. This implicates that it might be feasible to strengthen self-efficacy feelings for those patients who prefer to participate in MDM, but do not feel competent to communicate with their oncologist, or to stimulate bringing family members during consultations.

Feelings of loneliness did neither relate to patients age. Although it was expected that the lack of a satisfactory supportive system among elderly patients may contribute to greater feelings of loneliness (Alon, 2011), literature also states that an estimated 20-50% of geriatric patients have family caregivers (spouses, children), with whom they share their diagnosis and current condition. Often, these caregivers are highly motivated to help their family member manage the disease (Amalraj et al., 2009; Clayman et al., 2005).

When considering the variable temporal perspective, the stated hypothesis that 'middle aged' patients (40-64 years) tend to be more future oriented than 'old elderly' patients (≥ 75 years) and vice versa, was not confirmed in this study. Explanations can be found in the knowledge that palliative cancer patients face a premature death, which might shorten patients' temporal perspective.

Considering the age-related aspects and their associations with participation in MDM, greater feelings of self-efficacy in interaction with their oncologist were significantly related towards perceived SDM. This finding is in accordance with existing literature, stating that self-efficacy is a powerful predictor of patient participation in MDM (Maly et al., 2004; Légaré et al., 2008).

4.1.6 Demographics and decision-making

None of the demographics in this study, yielded associations with preferences for participation. This is in accordance with the systematic review of Hubbard et al. (2008), which concluded that the majority of the included studies did not report associations between role preferences and gender as well as education level. Contrasting results concluded that patients with lower levels of education prefer less involvement (Bastiaens et al., 2007; De Haes, 2006; Doherty & Doherty, 2005). Also, a majority of studies included in the review of Hubbard et al. (2008) found associations between marital status and role preferences, with married people being more likely to prefer an active role in MDM. The present study was not able to establish the same finding.

Significant associations were found between gender and perceived participation roles, with the majority of males perceiving patient centeredness, whereas the majority of females perceived SDM. Literature on *perceived* participation roles and gender is scarce, however it is known that females in general prefer SDM, as compared to males who prefer an active (patient centered) role in MDM (Levinson et al., 2005).

4.2 Strengths and limitations

The cross-sectional study design was suitable for the objective of this study, since its aim was to establish associations instead of causality. However, due to time frame discrepancies, other factors may have been influencing the studied relationship between variables. Also, due to the retrospective nature of the questionnaire, recall bias might be prevalent. Therefore, this study could be improved by performing a longitudinal study, because that research design is more robust for such violations.

Another potential bias stems from the research setting. Patients might have responded to the questions about the quality of care more positively if they believed that their oncologist was aware of their participation. This finding is in line with Grunfeld et al. (2006) who stated that patients may not want to appear negative about the oncologist who was working to improve their quality of life and potentially prolong their life. This was anticipated for, by guarantying anonymity of the results. However, it is impossible to say whether this potential bias may still be present despite the precautions taken.

Furthermore, consecutive sampling (non-probability) was used to select eligible participants. In order to answer the question how well the sample represents the population, various considerations can be made. Only participants who were undergoing chemotherapy were included in this study, while patients who refused chemotherapy may have different preferences for participation in MDM. In addition, this study was performed in palliative cancer care. Results valid for this sample are not necessarily generalizable to other types of cancer, or other stages of the cancer. Patients undergoing chemotherapy for curative or adjuvant purposes might respond different, since it was concluded that palliative patients might be expert patients and therefore are more likely to take an active role (Grunfeld et al., 2006). Nevertheless, due to the low non-response rate, external generalizability of the findings in this study is considered to be moderate.

Another limitation relates to the finding that some participants felt that the decision whether or not to enter life prolonging chemotherapy was ‘not a real choice’. The chemotherapy involved no cure and few participants thought that no appropriate alternative existed. The literature recognizes this finding and reports that perceiving there is no decision to be made is a barrier towards SDM (Joseph-Williams et al., 2014; Brom et al., 2014). Therefore, this study emphasizes the need for oncologists to express that doing nothing is also an option and inform the patient about supportive care alternatives and symptom management.

From a methodological point of view, two factors could have contributed to the non-significant findings between participation in MDM and age, as well as the variables HR-QoL, self-efficacy, loneliness and temporal perspective and age. The small sample size might have influenced this. Also, limited age differences between the age groups could have biased potential age differences.

A remark that has to be made is that this study has an individual oriented, life span perspective. However, it should be noted that cohort effects in general may also influence participation roles in MDM, because people who are born in different decades are exposed to different values and socialization processes. For example, elderly people are often described to stem from a generation who easily accept the authority of a physician (Bastiaens et al., 2007).

4.3 Scientific and clinical relevance

This study demonstrated its scientific relevance 1) by its focus on a *life span perspective*. Consequently, this study created an understanding of the impact of age in MDM, addressing potential age-related barriers and facilitators towards participation in MDM. Moreover, by addressing a life span perspective, information was provided 2) towards MDM among *elderly cancer patients*, which was badly needed given the lack of studies that focus on MDM within this age group (Price et al., 2012; Mandelblatt, Kreling, Figeuriedo & Feng, 2006). Also, this study is scientifically relevant, since it is 3) one of few studies addressing patient participation in MDM in *a palliative setting*.

From a clinical point of view, the most important contribution of this study relates to the awareness that regardless of age, cancer patients with metastatic diseases preferred (and are perceived to be) actively involved in MDM. Since almost 20% of patients was less involved than preferred, a recommendation for clinical practice is therefore to avoid a paternalistic decision-making style.

While this study creates a better understanding of patients who may benefit from participation in MDM, oncologists should avoid to in- or exclude patient participation in MDM based on demographics. From an ethical imperative, this study stresses the importance of literally asking patients' towards their participation preferences in MDM. Hence, patients can achieve their desired level of involvement.

Literature underlines some ethical concerns, stating that cancer patients in a palliative setting might face additional challenges in order to be involved in MDM, due to complex treatment decisions, shortened life expectancy, treatment-related toxicities, unguaranteed benefits and physical and emotional distress (Leighl, Butow & Tattersall, 2004; Gattellari et al., 2002). Also, patients' MDM capacity can be impaired due to fatigue, physical deterioration, medical complications or drug-induced cognitive impairments (Addington-Hall, 2002; Rees, 2001). Moreover, SDM in a palliative setting has been associated with decisional conflict and increased anxiety (Gattellari et al., 2002; Gaston & Mitchell, 2005). Some patients might lack the confidence of making the best decision and fear decision regret. Therefore patients might be willing to place the physician in control (Keating et al., 2010).

Although within this study no evidence was found suggesting that SDM might not be feasible in palliative cancer care, the possible presence of these barriers should however be taken into account. This suggests that it is important that even if patients prefer a passive role, oncologists will attempt to involve personal preferences and values of the patient in the MDM process.

4.4 Future directions

The influence of age on participation in MDM did not as clearly emerge as expected. The palliative nature of the study is assumed to have influenced this. Therefore, future research could address patient participation from a life span perspective in a *curative* setting.

Also, future studies do well using a larger sample size and a larger dispersion of age differences across age groups. Other improvements can be realized by performing an observational study, since data in this study was gathered by means of self-report, which can bias the results.

Furthermore, future research would benefit by including oncologists, since knowledge of oncologists’ views is limited with regards to SDM, yet oncologists are of significant importance because they can either facilitate or hinder patient participation in MDM (Shepherd, Butow & Tattersall, 2011). The limited insight that the present study gained with respect to the role of oncologists, stems from a patients' perspective. Therefore, valid conclusions about oncologists’ behavior could not be made.

Finally, future studies do well addressing more specifically patients’ social context, since it is known that significant others such as spouses and children (besides the physician/oncologist) can have impact on the decision to participate (Stiggelbout et al., 2007).

The main conclusion of this study is that no age-related differences were found in patients’ preferred- and perceived level of involvement in MDM, as well as levels of concordance. The palliative setting of this study was mainly expected to be responsible for these non-existing age differences, as is appropriately expressed with the following quote:

> *‘An important consideration is the extent to which differences between people are cancelled out in the final stages of life.’* (Lloyd, 2004, p.240)

However, perceived SDM was associated with female gender, as well as greater feelings of self-efficacy in communication with oncologists. The results of this study demonstrated that a large majority of patients (regardless of their age), preferred- and perceived an active or collaborative role. As a result, it can be stated that SDM in palliative cancer care might be feasible for those patients who want to be involved in MDM, suggesting that the use of a paternalistic style should be avoided. However, since 1 out of 5 patients did not want to participate in MDM and nearly 20 % of patients was less involved than preferred, this study stresses the importance of asking patients preferences for involvement, so that patients’ preferences for involvement are met. Moreover, even if patients do not want to be involved in MDM, oncologists must still make an effort to gain an understanding of patient characteristics and values. Consequently, patients’ concerns and wishes are elicited and treatments can be tailored with respect to individual patient characteristics and preferences.

To the researchers’ knowledge, this is the first study addressing simultaneously the lack of knowledge about SDM in palliative cancer care, as well as the influence of age in MDM, by means of a life span perspective.

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APPENDICES

Appendix A: Questionnaire

Vragenlijst medische besluitvorming

Dit is de vragenlijst behorende bij het onderzoek naar medische besluitvorming bij kankerpatiënten. Allereerst worden er een aantal algemene gegevens verzameld. Vervolgens worden er een aantal vragen gesteld die meer specifiek gericht zijn op het besluit over het wel of niet aangaan van een chemokuur. Naar verwachting duurt het invullen van de vragenlijst ongeveer 20 minuten.
De vragen in de vragenlijst zijn grotendeels meerkeuzevragen. Hierbij hoeft u alleen een kruisje te zetten op de juiste plek. Voorbeeld:

☒ Ja
☐ Nee

Wanneer u uw antwoord wilt *corrigeren* kunt u dat doen door het juiste antwoord te omcirkelen. Voorbeeld:

☒ Ja

☒ Nee

(In dit geval is het omcirkelde antwoordhokje het juiste antwoord)

Als u nog vragen heeft, kunt u contact opnemen met Claudia Groot Kormelinck,
email: c.m.grootkormelinck@student.utwente.nl of telefonisch 06-46283371.

Alvast hartelijk bedankt voor uw medewerking!

UNIVERSITEIT TWENTE.

MST

Demografische gegevens

Vragen 1 t/m 5 worden gesteld om een aantal persoonlijke kenmerken en uw huidige leefsituatie in kaart te brengen. Zodoende kan worden vastgesteld of de mensen, die meedoen aan dit onderzoek, een goede afspiegeling zijn van de bevolking.

1:	Wat is uw leeftijd?	☐ .... jaar
2:	Wat is uw geslacht?	☐ Man ☐ Vrouw
3:	Wat is uw nationaliteit?	☐ Nederlands ☐ Anders, namelijk ....
4:	Wat is uw burgerlijke staat?	☐ Alleenstaand (bijvoorbeeld vrijgezel, weduwe/weduwnaar of gescheiden) ☐ Samenwonend (bijvoorbeeld gehuwd of geregistreerd partnerschap)
5:	Wat is uw hoogst voltooide opleiding?	☐ Geen opleiding ☐ Lagere school / basisschool ☐ Lager beroepsonderwijs (LBO), huishoudschool ☐ VMBO, MAVO, ULO, MULO ☐ HAVO, MMS ☐ VWO, HBS, Gymnasium ☐ Middelbaar beroepsonderwijs (MBO), MTS, MEAO ☐ Hoger beroepsonderwijs (HBO), HEAO, HTS ☐ Wetenschappelijk onderwijs, universiteit, of hoger

KWALITEIT VAN LEVEN

Wij zijn geïnteresseerd in uw gezondheid en de mate waarin u uw gezondheid waardeert, de ‘kwaliteit van leven’. Wilt u alle vragen beantwoorden door het getal te omcirkelen dat het meest op u van toepassing is? Er zijn geen ‘juiste’ of ‘onjuiste’ antwoorden.

Gedurende de afgelopen week:

		Helemaal niet	*Een beetje*	*Nogal*	*Heel erg*
6:	Heeft u moeite met het doen van inspannende activiteiten zoals het dragen van een zware boodschappentas of een koffer?	1	2	3	4
7:	Heeft u moeite met het maken van een lange wandeling?	1	2	3	4
8:	Heeft u moeite met het maken van een korte wandeling buitenshuis?	1	2	3	4
9:	Moet u overdag in bed of op een stoel blijven?	1	2	3	4
10:	Heeft u hulp nodig met eten, aankleden, uzelf wassen of naar het toilet gaan?	1	2	3	4

Gedurende de afgelopen week:

		Helemaal niet	*Een beetje*	*Nogal*	*Heel erg*
11:	Was u beperkt bij het doen van uw werk of andere dagelijkse bezigheden?	1	2	3	4
12:	Was u beperkt in het uitoefenen van uw hobby’s of bij andere bezigheden die u in uw vrije tijd doet?	1	2	3	4
13:	Was u kortademig?	1	2	3	4
14:	Heeft u pijn gehad?	1	2	3	4
15:	Had u behoefte om te rusten?	1	2	3	4
16:	Heeft u moeite met slapen gehad?	1	2	3	4
17:	Heeft u zich slap gevoeld?	1	2	3	4
18:	Heeft u gebrek aan eetlust gehad?	1	2	3	4

Gedurende de afgelopen week:

		Helemaal niet	*Een beetje*	*Nogal*	*Heel erg*
19:	Heeft u zich misselijk gevoeld?	1	2	3	4
20:	Heeft u overgegeven?	1	2	3	4
21:	Had u last van obstipatie? (Was u verstopt?)	1	2	3	4
22:	Had u diarree?	1	2	3	4
23:	Was u moe?	1	2	3	4
24:	Heeft pijn u gehinderd in uw dagelijkse bezigheden?	1	2	3	4
25:	Heeft u moeite gehad met het concentreren op dingen, zoals een krant lezen of televisie kijken?	1	2	3	4
26:	Voelde u zich gespannen?	1	2	3	4
27:	Maakte u zich zorgen?	1	2	3	4
28:	Voelde u zich prikkelbaar?	1	2	3	4
29:	Voelde u zich neerslachtig?	1	2	3	4
30:	Heeft u moeite gehad met het herinneren van dingen?	1	2	3	4
31:	Heeft uw lichamelijke toestand of medische behandeling uw familieleven in de weg gestaan?	1	2	3	4
32:	Heeft uw lichamelijke toestand of medische behandeling u belemmerd in uw sociale bezigheden?	1	2	3	4
33:	Heeft uw lichamelijke toestand of medische behandeling financiële moeilijkheden met zich meegebracht?	1	2	3	4

Wilt u voor de volgende vragen het getal tussen 1 en 7 omcirkelen dat het meest op u van toepassing is:

34: Hoe zou u uw algehele gezondheid gedurende de afgelopen week beoordelen?

1	2	3	4	5	6	7
Erg slecht						*Uitstekend*

35: Hoe zou u uw algehele 'kwaliteit van het leven' gedurende de afgelopen week beoordelen?

1	2	3	4	5	6	7
Erg slecht						*Uitstekend*

Belangrijkste behandelaar
De volgende vraag is bedoeld om inzicht te krijgen in wie van de medische staf, in uw geval, het meest betrokken is geweest bij het besluit over het wel of niet aangaan van een chemokuur.

36: Welke arts is in uw geval het meest betrokken geweest bij het besluit om wel of geen chemokuur aan te gaan?

☐ Internist oncoloog/ hematoloog ☐ Chirurg ☐ Anders, namelijk ____________________

BEHOEFTE OM MEE TE BESLISSEN

Bij een ziekte als kanker moeten soms moeilijke beslissingen worden genomen. Vraag 37 gaat over het moment waarop u voor de keuze heeft gestaan om *wel of geen chemokuur* aan te gaan. Als u meerdere keren voor deze keuze heeft gestaan, willen wij u vragen terug te denken aan de meest recente situatie. In hoeverre heeft u toen de *BEHOEFTE* gehad om mee te beslissen over het wel of niet aangaan van een chemokuur (het gaat hier dus *niet* om de vraag of u daadwerkelijk heeft meebeslist). Waar *'oncoloog'* genoemd staat, neemt u de persoon in gedachten die u zojuist hebt ingevuld bij vraag 36.

37: Bekijkt u alstublieft de volgende vijf afbeeldingen. Kies er *één* die het beste aansluit bij hoe u wilt dat de beslissing over het wel of niet aangaan van een chemokuur wordt gemaakt. Mijn voorkeur wordt het beste weergegeven in afbeelding:

☐A ☐B ☐C ☐D ☐E


Ik geef er de voorkeur aan dat ik de definitieve beslissing maak over het wel of niet aangaan van een chemokuur.


Ik geef er de voorkeur aan dat ik de definitieve beslissing maak over het wel of niet aangaan van een chemokuur, nadat ik serieus de mening van mijn oncoloog heb overwogen.


Ik geef er de voorkeur aan dat mijn oncoloog en ik de verantwoordelijkheid delen bij de beslissing over het wel of niet aangaan van een chemokuur.


Ik geef er de voorkeur aan dat mijn oncoloog de definitieve beslissing maakt over het wel of niet aangaan van een chemokuur, maar mijn mening is hierin meegenomen.


Ik geef er de voorkeur aan dat mijn oncoloog de definitieve beslissing maakt over het wel of niet aangaan van een chemokuur.

Rol oncoloog

Nu worden er een aantal vragen gesteld die betrekking hebben over hoe het besluit is gemaakt voor het wel of niet aangaan van een chemokuur. Vraag 38 tot en met 42 gaan over de rol die uw oncoloog heeft gehad in dit proces.

Het gaat hier om hoe u de rol van de oncoloog heeft waargenomen.

Kiest u alstublieft bij iedere stelling uit de antwoorden 'Ja' of 'Nee'.

		Ja	*Nee*
38:	Mijn oncoloog heeft me gevraagd of ik het eens ben met zijn/haar voorstel voor het wel of niet aangaan van een chemokuur.	☐	☐
39:	Mijn oncoloog heeft me aangemoedigd om over mijn zorgen te praten	☐	☐
40:	Mijn oncoloog heeft me aangemoedigd om mijn mening te geven over de chemokuur.	☐	☐
41:	Mijn oncoloog gaf me een goede uitleg over mijn klachten en de chemokuur behandeling.	☐	☐
42:	Mijn oncoloog heeft me gevraagd naar wat naar mijn mening de oorzaken van mijn klachten zijn.	☐	☐

Eigen rol

Vraag 43 tot en met 50 gaan over hoe u uw eigen rol heeft waargenomen tijdens het proces waarin u voor de keuze stond voor het wel of niet aangaan van een chemokuur.

		Ja	*Nee*
43:	Ik heb mijn oncoloog gevraagd om de details van de chemokuur aan mij uit te leggen.	☐	☐
44:	Ik heb mijn oncoloog gevraagd om adviezen voor mijn klachten.	☐	☐
45:	Ik heb uitgebreid verteld over mijn klachten.	☐	☐
46:	Ik heb mijn oncoloog veel vragen gesteld over mijn klachten.	☐	☐
47:	Ik heb zelf een bepaalde behandeling voorgesteld aan mijn oncoloog.	☐	☐
48:	Ik heb er op aangedrongen bij mijn oncoloog om een bepaald soort test of een behandeling te krijgen.	☐	☐
49:	Ik heb twijfels geuit over de chemokuur die mijn oncoloog heeft aanbevolen.	☐	☐
50:	Ik heb mijn mening gegeven over het wel of niet aangaan van de chemokuur.	☐	☐

Informatievoorziening
Onderstaande vragen brengen in kaart of u voldoende informatie heeft gekregen over diverse behandelingsmogelijkheden (voor u de keuze heeft gemaakt om wel of geen chemokuur aan te gaan). Geeft u alstublieft aan in hoeverre u het eens bent met de volgende uitspraken.

		Zeer oneens	Oneens	Neutraal	Eens	Zeer eens
51:	Ik was op de hoogte van alle behandelingsmogelijkheden.	☐	☐	☐	☐	☐
52:	Ik was op de hoogte van de voordelen van alle behandelingsmogelijkheden.	☐	☐	☐	☐	☐
53:	Ik was op de hoogte van de risico’s en bijwerkingen van alle behandelingsmogelijkheden.	☐	☐	☐	☐	☐

WAARGENOMEN MANIER – HOE IS HET BESLISSINGSPROCES GEGAAN?

Vraag 54 gaat wederom over het moment waarop u voor de keuze heeft gestaan om wel of geen chemokuur aan te gaan. Nu gaat het er wel om wie de beslissing heeft genomen over het wel of niet aangaan van een chemokuur. Bij deze vraag gaat het dus *niet om uw behoefte* om mee te beslissen, maar om uw *WAARNEMING*.

54: Bekijkt u alstublieft de volgende vijf afbeeldingen op deze pagina en de volgende pagina. Kies er vervolgens één die het beste aansluit bij uw ervaring van hoe de beslissing is gemaakt over het wel of niet aangaan van een chemokuur.
De manier waarop het besluit is gemaakt wordt het beste weergegeven in afbeelding:
☐A ☐B ☐C ☐D ☐E


Ik heb de definitieve beslissing gemaakt over het wel of niet aangaan van een chemokuur.


Ik heb de definitieve beslissing gemaakt over het wel of niet aangaan van een chemokuur, nadat ik serieus de mening van mijn oncoloog heb overwogen.


Mijn oncoloog en ik hebben de verantwoordelijkheid gedeeld over de beslissing van het wel of niet aangaan van een chemokuur.


Mijn oncoloog heeft de definitieve beslissing gemaakt over het wel of niet aangaan van een chemokuur, maar mijn mening is hierin meegenomen.


Mijn oncoloog heeft de definitieve beslissing gemaakt over het wel of niet aangaan van een chemokuur.

De volgende vragen gaan over hoeveel vertrouwen u in het algemeen heeft om als patiënt met uw oncoloog te communiceren. Wilt u bij iedere vraag aangeven hoeveel vertrouwen u er in heeft dat u in staat bent om dit uit te voeren?
Wanneer u hier helemaal geen vertrouwen in heeft, kruist u het meest linkse hokje aan:
Helemaal geen vertrouwen* ☐ ☐ ☐ ☐ ☐ *Heel veel vertrouwen
Hoe meer vertrouwen u erin heeft, hoe meer u uw kruisje in de richting van 'Heel veel vertrouwen' plaatst.

	Hoeveel vertrouwen heeft u er in dat u …	*Helemaal geen vertrouwen*				*Heel veel Vertrouwen*
55:	weet welke vragen u uw oncoloog moet stellen?	☐	☐	☐	☐	☐
56:	in staat bent om uw oncoloog al uw vragen te laten beantwoorden?	☐	☐	☐	☐	☐
57:	het bezoek aan uw oncoloog optimaal weet te benutten?	☐	☐	☐	☐	☐
58:	in staat bent om uw oncoloog uw belangrijkste klachten serieus te laten nemen?	☐	☐	☐	☐	☐
59:	in staat bent om uw oncoloog iets aan uw belangrijkste klachten te laten doen?	☐	☐	☐	☐	☐

Onderstaande vragen zijn gericht op u en de mensen in uw directe omgeving.
Het is van belang om inzicht te krijgen in de persoonlijke waardering van bestaande relaties. Kruist u alstublieft het antwoord aan dat het meest op u van toepassing is.

		Zeker	*Ja*	*Min of meer*	*Nee*	*Zeker niet*
60:	Ik ervaar een leegte om mij heen.	☐	☐	☐	☐	☐
61:	Er zijn genoeg mensen op wie ik in geval van narigheid kan terugvallen.	☐	☐	☐	☐	☐
62:	Ik heb veel mensen op wie ik volledig kan vertrouwen.	☐	☐	☐	☐	☐
63:	Er zijn genoeg mensen met wie ik mij nauw verbonden voel.	☐	☐	☐	☐	☐
64:	Ik mis mensen om me heen.	☐	☐	☐	☐	☐
65:	Vaak voel ik me in de steek gelaten.	☐	☐	☐	☐	☐

De laatste paar vragen hebben erop betrekking hoe u denkt als het om het verleden, heden en toekomst gaat.
U kunt kiezen uit 7 antwoorden, variërend van 'nooit' naar 'continu'. Hoe meer de uitspraak op u van toepassing is, hoe meer u uw kruisje in de richting van 'continu' plaatst.

		1 *Nooit*	*2*	*3* *Soms*	*4*	*5* *Vaak*	*6*	*7* *Continu*
66:	Ik denk aan dingen van mijn verleden.	☐	☐	☐	☐	☐	☐	☐
67:	Ik leef mijn leven in het hier en nu.	☐	☐	☐	☐	☐	☐	☐
68:	Ik denk na over wat de toekomst mij gaat brengen.	☐	☐	☐	☐	☐	☐	☐
69:	Ik richt mij op wat zich momenteel afspeelt in mijn leven.	☐	☐	☐	☐	☐	☐	☐
70:	Ik richt mij op de toekomst.	☐	☐	☐	☐	☐	☐	☐
71:	Ik haal oude herinneringen weer voor de geest.	☐	☐	☐	☐	☐	☐	☐
72:	Ik stel me voor wat de dag van morgen me zal brengen.	☐	☐	☐	☐	☐	☐	☐
73:	Mijn geest is in het hier en nu.	☐	☐	☐	☐	☐	☐	☐
74:	Ik reflecteer op wat er in mijn leven is gebeurd.	☐	☐	☐	☐	☐	☐	☐
75:	Ik denk na over waar ik vandaag ben.	☐	☐	☐	☐	☐	☐	☐
76:	Ik denk terug aan vroegere tijden.	☐	☐	☐	☐	☐	☐	☐
77:	Ik denk aan de tijd die nog zal komen.	☐	☐	☐	☐	☐	☐	☐

Zijn er naar uw mening nog dingen die het MST zou kunnen verbeteren als het gaat om het betrekken van patiënten bij een keuze voor een behandeling?

....

....

....

....

....

....

Indien u nog op- of aanmerkingen heeft, kunt u die hier vermelden:

....

....

....

....

....

....

Dit is het einde van de vragenlijst. Hartelijk dank voor uw deelname!

Indien u op de hoogte gehouden wilt worden over de resultaten van deze vragenlijst, dan kunt u hieronder uw contactgegevens vermelden. Deze gegevens worden uitsluitend gebruikt om u te informeren over deze resultaten.

Naam: ....

Adres: ....

Postcode: ....

Woonplaats: ....

Emailadres: ....

Appendix B: Information Letter & Informed Consent

UNIVERSITEIT TWENTE.

MST

Enschede, 12 januari 2015

Informatiebrochure: gedeelde besluitvorming bij kankerpatiënten

Geachte mevrouw/mijnheer,

Zoals mogelijk het geval is, heeft uw behandelend arts u ingelicht over een lopend onderzoek binnen de afdeling oncologie. Dit onderzoek richt zich op medische besluitvorming bij kankerpatiënten en is gebaseerd op een samenwerking tussen het Medisch Spectrum Twente en Universiteit Twente. Voordat u al dan niet toestemming geeft tot deelname, is het van belang dat u informatie krijgt over dit onderzoek. In deze brochure vindt u alle benodigde informatie over het onderzoek, getiteld 'gedeelde besluitvorming bij kankerpatiënten'.

Achtergrond
Kanker is een veelvoorkomende ziekte en door de vergrijzing zal het aantal kankerpatiënten de komende jaren verder oplopen. Desondanks is er weinig informatie bekend over de manier waarop medische besluiten worden gemaakt. Dit onderzoek richt zich op patiënten van 40 jaar en ouder.

Doel
Doel van dit onderzoek is het inzicht krijgen in de huidige manier van medische besluitvorming binnen het MST. Daarbij wordt gekeken naar overeenkomsten en verschillen in besluitvorming tussen kankerpatiënten van verschillende leeftijden.

Wanneer komt u in aanmerking voor dit onderzoek?
U komt in aanmerking om deel te nemen aan dit onderzoek wanneer u gediagnosticeerd bent met kanker en voor de keuze heeft gestaan om wel of geen chemokuur te ondergaan. Deelnemen kan vanaf 40 jaar en ouder.

Onderzoeksprocedure
Wanneer u besluit deel te nemen aan het onderzoek, wordt u gevraagd eenmalig een vragenlijst in te vullen. Naar verwachting duurt het invullen van de vragenlijst ongeveer twintig minuten.

Belasting en risico's
Dit onderzoek levert geen extra belasting of risico's voor u op.

Mogelijke voordelen

Deelname aan dit onderzoek zal geen directe persoonlijke voordelen opleveren. Deelname draagt wel bij aan verbetering van het besluitvormingsproces, waar in de toekomst kankerpatiënten voordeel van kunnen hebben.

Deelname

Deelname aan het onderzoek geschiedt op vrijwillige basis. Mocht er een vraag gesteld worden waarop geen antwoord wenst gegeven te worden, dan wordt dit gerespecteerd.
Ook indien u nu toestemming geeft, kunt u te allen tijde uw toestemming zonder opgaaf van redenen weer intrekken. Uw besluit zal geen enkele verandering teweeg brengen in de verzorging en begeleiding van u en uw naasten.

Privacy

De verzameling van de gegevens worden versleuteld verwerkt. Dit betekent dat het niet zichtbaar is welke gegevens afkomstig zijn van welke patiënt. Zodoende wordt uw privacy gewaarborgd. Tevens zullen uw gegevens niet naar derden worden gecommuniceerd, zonder uw uitdrukkelijke toestemming. Indien er belangstelling is voor de analyse van de resultaten van het onderzoek, dan bestaat er de mogelijkheid om hier na afloop van het volledige onderzoek inzicht in te krijgen. Als dit het geval is, kunt u dit aangeven op de vragenlijst.

Ondertekenen toestemmingsformulier

Als u besluit mee te werken aan het onderzoek, onderteken dan het bijgesloten toestemmingsformulier. Hiermee bevestigt u uw voornemen om aan het onderzoek deel te nemen. De uitvoerende onderzoeker ondertekent dit formulier eveneens. Zodoende wordt bevestigd dat u deze informatiebrief is overhandigd en de onderzoeker verklaart op deze manier akkoord te gaan met het beantwoorden van eventueel nog opkomende vragen van uw kant. Voor vragen kan u zich wenden tot mevr. C.M. Groot Kormelinck (telefoon 06-46283371 of e-mail: c.m.grootkormelinck@student.utwente.nl).

Met vriendelijke groet,

Claudia Groot Kormelinck *(uitvoerend onderzoeker)*

Mede namens betrokken senior onderzoekers:

Dr. A.N.M. Wymenga *(Medisch Spectrum Twente)*
Dr. C. Bode *(Universiteit Twente)*
Dr. C.H.C. Drossaert *(Universiteit Twente)*

Toestemmingsverklaring

‘Gedeelde besluitvorming bij kankerpatiënten’

Onderzoeker: Claudia Groot Kormelinck

Te lezen en in te vullen door de deelnemer

Ik verklaar hierbij dat ik de informatiebrochure over het onderzoek naar ‘gedeelde besluitvorming bij kankerpatiënten’ heb gelezen. Ik heb de informatie begrepen en ben zodoende op een voor mij duidelijke wijze ingelicht over de aard, methode, doel en belasting van het onderzoek. Ik heb over mijn deelname na kunnen denken en ben in staat gesteld om vragen te stellen. Mijn vragen zijn naar tevredenheid beantwoord.

Door het ondertekenen van dit formulier geef ik toestemming voor deelname aan bovengenoemd onderzoek. Ik ga ermee akkoord dat de gegevens gebruikt worden voor wetenschappelijke doeleinden en ik ben mij ervan bewust dat de gegevens en resultaten van het onderzoek in anonimiteit en op vertrouwelijke wijze worden behandeld. Mijn persoonsgegevens zullen niet door derden worden ingezien tenzij ik hier uitdrukkelijk toestemming voor geef.

Als ik nog verdere informatie over het onderzoek zou willen krijgen, nu of in de toekomst, kan ik me wenden tot mevr. C.M. Groot Kormelinck (telefoon 06-46283371 of e-mail: c.m.grootkormelinck@student.utwente.nl).

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Mijn toestemming tot deelname kan ik op ieder moment intrekken, zonder opgaaf van redenen.

Voor eventuele klachten over dit onderzoek kan ik me wenden tot de secretaris van de Commissie Ethiek van de faculteit Gedragswetenschappen van de Universiteit Twente, mevr. J. Rademaker (telefoon: 053-4894591; e-mail: j.rademaker@utwente.nl).

Datum:	*Naam deelnemer:*	*Handtekening deelnemer:*
....	....	....

In te vullen door de uitvoerende onderzoeker

Ik heb een schriftelijke toelichting gegeven op het onderzoek. Resterende vragen over het onderzoek zal ik naar vermogen beantwoorden. De deelnemer zal geen nadelige gevolgen ondervinden in het geval er wordt afgezien van deelname van het onderzoek – of indien er sprake is van voortijdige beëindiging.

Datum:	*Naam onderzoeker:*	*Handtekening onderzoeker:*
....	....	....

Appendix C: Tables

Table 6a: Means and standard deviations of doctor facilitation, patient information, patient decision-making and information subscales; split by age groups (n=77)

Subscales	**Age groups**						**Total**	
	40-64		**65-74**		**≥ 75**			
	n = 28		*n = 25*		*n = 24*		*n = 77*	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1:Doctor facilitation	3.79	(1.5)	3.40	(1.4)	3.04	(1.3)	3.43	(1.5)
2:Patient info	3.26	(1.1)	2.68	(1.2)	2.46	(1.3)	2.82	(1.2)
3:Patient decision making	1.30	(1.1)	1.08	(0.8)	1.04	(1.0)	1.14	(1.0)
4:Information	27.08	(18.8)	34.33	(19.7)	34.03	(22.0)	31.60	(20.2)

Range doctor facilitation scale range: 0 and 5. Range of patient info and patient decision-making scale: 0 and 4. Higher scores reflects greater degrees of doctor facilitation/ patient involvement. Range information subscale: 0 (feels extremely informed) to 100 (feels extremely uninformed).

Table 6b: Kruskal-Wallis test for doctor facilitation, patient information, patient decision-making and information subscales; split by age groups (n=77)

Subscales	**p**
1:Doctor facilitation	0.17
2:Patient info	**0.04**
3:Patient decision making	0.69
4:Information	0.54

Significant p values are bold

Doctor facilitation, patient information exchange and patient decision-making decline a little as patients belonged to an older age group With respect to patient information, significant differences were found, with ‘old elderly’ patients (≥75 years) sharing significantly less information with their oncologist as compared to ‘middle aged’ patients (40-64 years).

Table 8: Means and standard deviations of HR-QoL: split by age groups (n=77)

Variable	**n**	**Age group**						**Total**	
Subscale		**40-64**		**65-74**		**≥75**			
		n = 28		*n = 25*		*n = 24*		*n = 77*	
		Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Health-related quality of life	77								
-Global QoL	77	62.8	(20.2)	55.7	(18.1)	64.6	(16.9)	61.0	(18.7)
-Physical function	77	74.0	(21.6)	71.7	(14.6)	70.6	(21.5)	72.2	(19.4)
-Role function	77	60.1	(32.5)	56.0	(26.7)	64.6	(28.4)	60.2	(29.3)
-Emotional function	77	68.2	(21.0)	75.3	(17.1)	72.9	(25.2)	72.0	(21.2)
-Cognitive function	76	84.5	(19.7)	82.6	(22.2)	79.2	(21.0)	82.2	(20.8)
-Social function	76	71.4	(27.9)	75.3	(23.6)	79.0	(27.2)	75.0	(26.2)
-Fatigue	77	43.3	(31.3)	45.8	(25.1)	41.2	(22.8)	43.4	(26.6)
-Nausea / vomiting	77	10.1	(21.0)	9.3	(21.6)	4.2	(8.9)	8.0	(18.3)
-Pain	77	28.0	(28.3)	21.3	(28.3)	26.4	(30.7)	25.3	(28.8)
-Dyspnoea	77	15.5	(26.4)	29.3	(29.4)	25.0	(26.5)	22.9	(27.7)
-Insomnia	77	40.5	(33.2)	33.3	(30.4)	31.9	(28.6)	35.5	(30.8)
-Appetite loss	77	27.4	(31.5)	20.0	(28.9)	27.8	(32.1)	25.1	(30.7)
-Constipation	77	16.7	(29.4)	14.7	(23.7)	12.5	(23.7)	14.7	(25.6)
-Diarrhoea	77	16.7	(30.8)	16.0	(29.1)	12.5	(23.7)	15.2	(27.9)
-Financial problems	77	15.5	(24.8)	12.0	(21.3)	4.2	(11.3)	10.8	(20.5)

Scores range between 0 – 100. Higher scores on functional scales represent higher levels of functioning. Higher scores on Global QoL represent higher levels of QoL. Higher scores on symptom scales represent higher levels of symptoms.

Table 9a: Means and standard deviations for self-efficacy, loneliness and temporal perspective; split by age groups (n=77)

Subscale	**n**	**40-64**		**65-74**		**≥75**		**Total**	
		n = 28		*n = 25*		*n = 24*		*n = 77*	
		Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1:Self-efficacy	77	20.6	(3.8)	19.8	(3.4)	19.5	(4.3)	20.0	(3.8)
2:Loneliness (total)	76	1.1	(1.9)	1.0	(1.5)	0.8	(1.1)	1.00	(1.6)
-Emotional loneliness	76	0.8	(1.3)	0.5	(0.9)	0.5	(0.9)	0.6	(1.1)
-Social loneliness	77	0.4	(0.9)	0.4	(0.8)	0.3	(0.8)	0.4	(0.8)
3:Temporal focus									
-Past focus	77	13.1	(3.1)	13.2	(3.9)	15.4	(4.1)	13.9	(3.8)
-Current focus	76	19.3	(4.6)	17.2	(5.0)	17.6	(5.2)	18.1	(5.0)
-Future focus	76	16.0	(5.6)	16.3	(5.4)	14.9	(4.8)	15.8	(5.2)

- *Scores on self-efficacy range between 5 - 25, with higher scores representing higher self-efficacy in communicating with the oncologist.*
- *Total scores on loneliness range between 0 - 6. Higher scores indicate higher levels of loneliness.*
- *Scores of each temporal focus subscale range between 4 - 28. Higher scores indicate a higher focus on the given time frame.*

Table 9b: Kruskal-Wallis test for self-efficacy, loneliness and temporal perspective; split by age groups (n=77)

Subscale	**p**
1: Self-efficacy	0.49
2: Loneliness (total)	0.93
- Emotional loneliness	0.83
- Social loneliness	0.48
3: Temporal focus	
- Past focus	0.16
- Current focus	0.43
- Future focus	0.62

Significant p values are bold

Table 10: Means and standard deviations for HR-QoL; split by preferred and perceived participation in decision-making (n=77)

HR-QoL	**Preferences**			**Perceived**		
Subscales	**Physician centered** *n = 14*	**Shared** *n = 29*	**Patient centered** *n = 34*	**Physician centered** *n = 23*	**Shared** *n = 22*	**Patient centered** *n = 32*
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
-Global QoL	61.3 (20.6)	61.2 (13.8)	60.8 (21.9)	59.4 (18.7)	61.4 (13.5)	62.0 (22.0)
-Physical function	79.5 (15.4)	70.8 (16.3)	70.4 (22.8)	72.2 (14.0)	74.2 (12.4)	70.8 (25.9)
-Role function	69.0 (26.0)	63.2 (28.7)	53.9 (30.4)	58.0 (27.0)	68.2 (27.2)	56.3 (31.9)
-Emotional function	69.6 (25.7)	70.1 (18.6)	74.5 (21.8)	69.9 (23.3)	71.6 (19.0)	73.7 (21.7)
-Cognitive function	89.3 (15.5)	78.2 (20.9)	82.8 (22.2)	86.2 (18.6)	79.5 (19.2)	81.2 (23.5)
-Social function	81.0 (21.5)	71.8 (24.0)	75.3 (29.8)	73.2 (22.3)	78.8 (23.1)	73.7 (31.0)
-Fatigue	35.7 (25.1)	46.7 (27.8)	43.8 (26.4)	41.5 (27.9)	41.9 (22.7)	45.8 (28.7)
-Nausea / vomiting	2.4 (6.1)	10.9 (16.2)	7.8 (22.6)	2.9 (6.5)	10.6 (18.2)	9.9 (23.1)
-Pain	16.7 (19.6)	25.9 (29.4)	28.4 (31.4)	28.3 (26.8)	22.0 (25.4)	25.5 (32.8)
-Dyspnoea	9.5 (20.4)	20.7 (24.3)	30.4 (31.1)	21.7 (29.5)	16.7 (19.9)	28.1 (30.7)
-Insomnia	38.1 (28.8)	35.6 (33.3)	34.3 (30.1)	47.8 (29.9)	27.3 (28.4)	32.3 (31.1)
-Appetite loss	26.2 (32.5)	24.1 (23.4)	25.5 (35.8)	31.9 (34.1)	27.3 (28.4)	18.8 (29.3)
-Constipation	14.3 (25.2)	18.4 (24.5)	11.8 (27.1)	27.5 (35.7)	12.1 (19.4)	7.3 (16.4)
-Diarrhoea	19.0 (36.3)	13.8 (22.7)	14.7 (28.7)	15.9 (29.9)	10.6 (21.5)	17.7 (30.5)
-Financial problems	2.4 (8.9)	14.9 (21.1)	10.8 (22.8)	5.8 (16.4)	10.6 (18.9)	14.6 (23.9)

** Scores range between 0 – 100. Higher scores on functional scales represent higher levels of functioning. Higher scores on Global QoL represent higher levels of QoL. Higher scores on symptom scales represent higher levels of symptoms.*

Table 11: Means and standard deviations for HR-QoL; split by levels of concordance (n=77)

	Less than preferred		**Concordance**		**More than preferred**		**Total**	
	n = 14		*n = 56*		*n = 7*		*n = 77*	
HR-QoL Subscales	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
-Global QoL	53.6	(16.2)	63.5	(18.8)	56.0	(20.2)	61.0	(18.7)
-Physical function	65.7	(8.6)	74.0	(20.2)	70.5	(26.3)	72.2	(19.4)
-Role function	45.2	(25.7	64.3	(28.9)	57.1	(33.1)	60.2	(29.3)
-Emotional function	70.2	(20.3)	72.5	(22.3)	71.4	(15.9)	72.0	(21.2)
-Cognitive function	84.5	(20.1)	81.5	(20.7)	83.3	(25.5)	82.2	(20.8)
-Social function	72.6	(23.2)	75.5	(27.0)	76.2	(28.6)	75.0	(26.2)
-Fatigue	49.2	(25.7)	41.3	(25.8)	49.2	(36.2)	43.4	(26.6)
-Nausea / vomiting	3.6	(7.1)	8.9	(20.8)	9.5	(8.9)	8.0	(18.3)
-Pain	39.3	(27.4)	21.7	(27.9)	26.2	(34.5)	25.3	(28.8)
-Dyspnoea	33.3	(29.2)	21.4	(28.0)	14.3	(17.8)	22.9	(27.7)
-Insomnia	47.6	(31.3)	33.3	(29.8)	28.6	(35.6)	35.5	(30.7)
-Appetite loss	38.1	(36.6)	23.2	(29.8)	14.3	(17.8)	25.1	(30.7)
-Constipation	33.3	(39.2)	9.5	(18.8)	19.0	(26.2)	14.7	(25.6)
-Diarrhoea	14.3	(28.4)	13.1	(26.0)	33.3	(38.5)	15.2	(27.9)
-Financial problems	7.1	(19.3)	11.3	(21.3)	14.3	(17.8)	10.8	(20.5)

**Scores range between 0 – 100. Higher scores on functional scales represent higher levels of functioning. Higher scores on Global QoL represent higher levels of QoL. Higher scores on symptom scales represent higher levels of symptoms.*

Table 13a: Means and standard deviations for self-efficacy, loneliness and temporal perspective; split by levels of concordance (n=77)

Variable Subscale	**Less than preferred**		**Concordance**		**More than preferred**		**Total**	
	n = 14		*n = 56*		*n = 7*		*n = 77*	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1: Self-efficacy in communication oncologist	19.7	(3.7)	20.4	(3.7)	17.3	(4.3)	20.0	(3.8)
2: Loneliness (total)	0.7	(1.6)	1.0	(1.4)	1.7	(2.4)	1.0	(1.6)
- Emotional loneliness	0.4	(0.8)	0.6	(1.0)	1.3	(1.6)	0.6	(1.1)
- Social loneliness	0.4	(0.8)	0.4	(0.8)	0.4	(1.1)	0.4	(0.8)
3: Temporal focus								
- Past focus	14.4	(2.9)	13.5	(3.9)	15.6	(4.6)	13.9	(3.8)
- Current focus	19.6	(3.0)	17.3	(5.1)	21.0	(5.4)	18.1	(5.0)
- Future focus	18.8	(5.3)	14.8	(4.9)	17.7	(5.4)	15.8	(5.2)

- *Scores on self-efficacy range between 5 and 25, with higher scores representing higher self-efficacy in communicating with the oncologist.*
- *Scores on loneliness range between 0 and 6. Higher scores represent higher levels of loneliness.*
- *Scores of each subscale of the temporal focus scale range between 4 and 28. Higher scores indicate a higher focus on the given time frame.*

Table 13b: Kruskal-Wallis test for self-efficacy, loneliness and temporal perspective; split by levels of concordance (n=77)

Variable Subscale	**P**
1: Self-efficacy in communication oncologist	0.17
2: Loneliness (total)	0.49
- Emotional loneliness	0.39
- Social loneliness	0.93
3:Temporal focus	
- Past focus	0.30
- Current focus	0.09
- Future focus	0.04

Significant p values are bold

Table 15: Crosstab and Pearson X^2 for concordance and demographics (n = 77)

	Less than preferred *n = 14*		**Concordance** *n = 56*		**More than preferred** *n = 7*		**Total** *n = 77*		$\mathbf{X^2}$	**p**
Demographics	n	(%)	n	(%)	n	(%)	n	(%)		
Gender									2.11	0.35
Male	5	(12.2)	32	(78.0)	4	(9.8)	41	(100.0)		
Female	9	(25.0)	24	(66.7)	3	(8.3)	36	(100.0)		
Marital status									0.57	0.75
Single	4	(20.0)	15	(75.0)	1	(5.0)	20	(100.0)		
Cohabit	10	(17.5)	41	(71.9)	6	(10.5)	57	(100.0)		
Education level									3.04	0.55
Low	9	(18.8)	36	(75.0)	3	(6.3)	48	(100.0)		
Medium	4	(26.7)	9	(60.0)	2	(13.3)	15	(100.0)		
High	1	(7.7)	10	(76.9)	2	(15.4)	13	(100.0)		

Significant p values are bold