

Relatives of patients with metastatic lung cancer's views on the achievement of treatment goals and the choice to start treatment: an interview study

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Abstract

Purpose. Lung cancer has a high impact on both patients and relatives. Previous studies looked into treatment goals patients have before starting a treatment. However, studies on relatives' perceptions of treatment at the end of life are scarce. Therefore, we studied the perspectives of relatives in hindsight on the achievement of treatment goals and the choice to start treatment for metastatic lung cancer of their loved one.

Methods. We conducted a semi-structured telephone interview study in six hospitals across the Netherlands, one academic and five non-academic hospitals between February 2017 and November 2019. We included 118 relatives of deceased patients diagnosed with metastatic lung cancer who started a systemic treatment and who completed a questionnaire on their treatment goals before start of the treatment and when treatment was finished. We asked the relatives about the achievement of patients' treatment goals and relatives' satisfaction with the choice to start treatment.

Results. Relatives reported the goals 'quality of life', 'decrease tumour size' and 'life prolongation' as achieved in 21%, 37% and 41% respectively. Most of the relatives (78%) were satisfied with the choice to start a treatment. Also, when none of the goals were achieved, 70% of the relatives were satisfied. About one in two relatives who were satisfied with the patient's choice did mention negative aspects of the treatment choice, such as that the treatment did not work, that there were side effects or that it would not have been the relatives choice. This was four in five for relatives who were not satisfied. Most mentioned positive aspects were that they tried everything and that it was the patient's choice.

Conclusion. Relatives reported patients' treatment goals as not achieved in a majority of cases. They were, however, in majority of the cases satisfied about the treatment choice. Being satisfied does not provide a full picture of their experience with the treatment decision as a majority mentions negative aspects of this decision. At the time of making the treatment decision it is important to manage expectations about chance of success and possible side effects of the treatment.

Introduction

Lung cancer is the world's leading cause of cancer death.¹ For patients with metastatic lung cancer, chemotherapy, immunotherapy and targeted therapy with tyrosine kinase inhibitors (TKIs) are possible treatments with the aim of relieving symptoms, temporary disease control and prolonging survival.²⁻⁵ People at the end of life often have diverse physical, psychological and social needs, as well as a need to prepare for death and achieve life closure.⁶⁻⁸ While patients and relatives attach great value to fulfilling these needs⁸, there is often hope for cure or life prolongation at the same time.^{9,10} A few studies found the following treatment goals that patients mentioned before starting a treatment for metastatic lung cancer: to improve or maintain quality of life, to prolong life, get comfort, to fight cancer and cure¹¹⁻¹³. Earlier we found that after treatment, patients reported in less than half of the time that these goals were achieved: quality of life for 30%, life prolongation for 49%, decrease tumour size for 26% and cure for

44%. Directly after the treatment was finished, most patients felt, in hindsight, that the right decision to start the treatment was made, even if the treatment goals were not achieved.¹⁰ Cancer has a large impact on both patients and relatives.^{14, 15} Relatives often accompany patients to a physician visit and help the patients obtain information relevant to medical treatments¹⁶⁻¹⁸. Relatives can have another evaluation on the choice to start treatment of the patient, and whether the goals are achieved. On the one hand, because they may witness the patient with metastasized lung cancer from diagnosis to death, and can also take into account the last phase of life when considering whether treatment goals are achieved and the right choice was made. On the other hand, because they have another perspective as being the relative and not the patient. Our objective was to study the perspective of relatives on the choice to start treatment for metastatic lung cancer of their relative in hindsight, more specifically after the patient had deceased. We specifically looked at (1) relatives' perspective of the achievement of patients' treatment goals, (2) relatives' view on the patients' choice to start treatment and (3) to what extent achievement of treatment goals and satisfaction with the patient's choice to start treatment are related to each other.

Methods

Study design and population

We conducted a semi-structured telephone interview study with relatives of deceased patients with metastatic lung cancer. This study is part of a larger study on goals patients with metastasized lung cancer and their oncologists have when starting a systemic treatment. In that part of the study patients and oncologists were asked to report their treatment goals before start of a systemic treatment and were asked to what extent these goals were achieved directly after treatment was finished and whether it was the right decision to start this treatment in hindsight.

We included relatives of above patients who died during the study period (See Mieras et al.). The telephone interview was conducted with relatives at least 6 weeks after the patient had died, all performed by one researcher (AM, between February 2017 and November 2019).

Data collection

Patients and relatives completed the informed consent form before the treatment started. During the structured telephone interviews, questions were read aloud and answers were documented. The interviews focused on the treatments goal(s) the patient reported before start of the treatment. During the interview relatives were asked to what extent they perceived the treatment goal(s) of the patient as achieved on a scale from 0 to 10, with 0 is not achieved at all and 10 is completely achieved. In total, 21 patients mentioned 'cure' as a treatment goal. Since only the relatives of deceased patients were included, we did not ask if the goal 'cure' was achieved so we excluded this treatment goal from the analysis. Additionally, a question on the satisfaction with the patients' choice for starting a treatment from their perspective and a question whether they thought they received enough information on the treatment were asked (see appendix). Age, gender and relation to the patient of the relatives were documented.

The time between patients' death and the interview with the relative was on average 86 days. As exception, one relative was interviewed 15 days after the patient died, instead of 6 weeks after the patient died, because the investigator did not know the patient had already died when she called for the study among patients. The relative preferred to do the interview at that time rather than later. The time between the last administration of treatment the patient received and the interview with the relative was on average 201 days .

Data analysis

Descriptive statistics were conducted using IBM SPSS statistics 24. Concerning the question to what extent the treatment goal(s) of the patient was achieved according to the relative, we perceived a goal as achieved if it was rated with a 7 or higher (on a 0 to 10 scale) (Mieras et al.). The question on the satisfaction with the treatment choice in hindsight was to be answered with 'yes', 'no' or 'I am not sure' and additionally open-ended for further explanation. The answers 'no' and 'I am not sure' were for analysis merged into 'not satisfied'. Answers to this open-ended question were categorized independently and subsequently compared by 4 research members (HRWP, BDO, AM, AB) The codes agreed upon were grouped in the categories 'positive aspects', 'negative aspects' and 'other aspects'. Discrepancies were resolved through discussion until 100% agreement was achieved.

Results

Participant recruitment In total, 266 patients started a treatment for metastatic lung cancer and completed the questionnaire on their treatment goals. Of these patients, 164 patients were deceased during the study period, resulting in 164 relatives being eligible for participation of which 118 (72%) participated in an interview (Fig. 1).

Characteristics of study participants

Participants had an average age of 62 years and ranged between 30 and 85 years. Most participants were female (63%) and partner of the patient (81%) (Table 1).

Table 1
Demographic characteristics of study
participants

Variable	N	%
Participants	118	100
Age – Years Mean ± SD Range	62 ± 11 30–85	
Sex Male Female	43 75	37 63
Relation to patient Partner Father/mother Son/daughter Sibling Friend	96 1 16 4 1	81 1 14 3 1

Table 2
Explanations of being satisfied with the treatment choice.

N column (%)	Total (n = 118) N (%)	Satisfied (n = 92) N (%)	Not satisfied* (n = 26) N (%)
Patients mentioned: **	47 (42)	42 (48)	5 (20)
• Only positive aspects	35 (31)	26 (30)	9 (36)
• Positive and negative aspects	31 (27)	19 (22)	11 (44)
• Only negative aspects			
Positive aspects mentioned	28 (24)	22 (24)	6 (23)
• We tried everything	17 (14)	11 (12)	6 (23)
• It was the patients' choice	16 (14)	15 (16)	1 (4)
• Lived longer	14 (12)	11 (12)	3 (12)
• The treatment worked	12 (10)	10 (11)	2 (8)
• No side effects	10 (8)	7 (8)	3 (12)
• It gives hope	6 (5)	6 (7)	0 (0)
• Good quality of life	3 (3)	3 (3)	0 (0)
• Other			
Negative aspects mentioned	23 (19)	17 (18)	6 (23)
• The treatment didn't work	15 (13)	11 (12)	4 (15)
• Side effects	12 (10)	5 (5)	7 (27)
• It was not my choice	10 (8)	3 (3)	7 (27)
• Quality of life worsened	9 (8)	4 (4)	5 (19)
• Treatment was given too long	5 (4)	3 (3)	2 (8)
• Burdensome hospital visits	4 (3)	4 (4)	0 (0)
• The treatment was started too late			
Other aspects mentioned	19 (16)	19 (21)	0 (0)
• Good quality of care	15 (13)	9 (10)	6 (23)
• Insufficient quality of care	13 (11)	11 (12)	2 (8)
• It was the choice of the oncologists	7 (6)	3 (3)	4 (15)
• I don't know how it would have been otherwise	3 (3)	3 (3)	0 (0)
• It helped science			
*Including relatives who reported "not sure" on the treatment satisfaction. ** 4% missing. Percentages don't add up to 100% since more answers were possible.			

Achievement of patients' treatment goals according to relatives

The 118 relatives of patients reported about the achievement of 143 treatment goals. Relatives most often reported the achievement of the treatment goal with 0 (not achieved at all) (n = 47). Relatives reported the goals 'quality of life', 'life prolongation' and 'decrease in tumour size' as achieved in 21%, 41% and 37% respectively (Fig. 2). In total, 76 relatives (64%) perceived none of the goals as achieved, for 42 relatives (36%) at least one of patients' goals was achieved, of whom 29 reported that all goals were achieved (25%) (data not shown).

Satisfaction with patients' choice to start treatment A total of 78% (n = 92) of the relatives was, in hindsight, satisfied with the patients' choice to start a treatment, 14% (n = 16) was not satisfied about the treatment choice and 9% (n = 10) was not sure. When asked to explain why they felt satisfied or not with the patients' treatment choice, relatives reported only positive aspects (42%), both positive and negative aspects (31%) or only negative aspects (27%). That relatives were satisfied did not mean they only mentioned positive aspects: 30% mentioned both positive and negative aspects and 22% mentioned only negative aspects. That relatives were not satisfied did not mean they only mentioned negative aspects: 36% mentioned both positive and negative aspects and 20% mentioned only positive aspects. Box 1 shows examples of answers given by relatives. The most frequently mentioned positive aspects were 'we tried everything' (24%), 'it was the patient's choice' (14%), and 'the patient lived longer' (14%). 'It was the patient's choice' was more frequently mentioned by relatives that were not satisfied with the treatment choice than relatives that were satisfied (23% versus 12%). 'The patient lived longer' was more frequently mentioned by relatives who were satisfied than relatives who were not (16% versus 4%). The most frequently mentioned negative aspects were 'the treatment did not work' (19%), 'there were side effects' (13%), and 'it was not my choice' (10%). The latter was more frequently mentioned by relatives that were not satisfied than relatives that were satisfied (27% versus 5%). Next to positive and negative aspects relatives also mentioned other aspects. This was often related to the quality of care; it could be perceived as good quality of care (16%) or insufficient quality of care (13%). Insufficient quality of care was more frequently mentioned by relatives who were not satisfied than relatives that were not (23% versus 10%). Good quality of care was only mentioned by relatives that were satisfied (21%). Most of the relatives (78%) were satisfied with the choice to start a treatment (n = 92). From the relatives who reported that at least one of patients' goals were achieved (n = 42), 93% was satisfied about the treatment choice. When none of the goals were achieved (n = 76), 70% of the relatives were satisfied.

Discussion

Relatives reported the goals 'quality of life', 'decrease tumour size' and 'life prolongation' as achieved in 21%, 37% and 41% respectively. Most of the relatives (78%) were satisfied about the patients' choice to start a treatment. Even if none of the goals were achieved, 70% of the relatives was satisfied. About one in two relatives who were satisfied with the patient's choice did mention negative aspects of the treatment choice, such as that the treatment did not work, that there were side effects or that it would not have been the relatives choice; this was four in five for relatives who were not satisfied with the patient's choice to start treatment. Most mentioned positive aspects were that they tried everything and that it was the patient's choice. About one in three relatives reported both positive and negative aspects of the treatment choice, independently of being satisfied or not.

Relatives consider patient's treatment goals less often achieved than patients. The patients for whom the relatives reported whether the treatment goals were achieved reported their predefined treatment goals 'quality of life', 'decrease tumour size', and 'life prolongation' achieved in 30%, 26% and 49% respectively.¹⁰ So, compared to patients, relatives consider the goals 'quality of life' (21% vs 30%) and 'life

prolongation' (41% vs 49%) less often achieved and 'decrease tumour size' (37% vs 26%) more often as achieved. Possible explanations for the difference in achievement can lie in the fact that relatives reported achievement of goals after the patient died taking into account the whole period or in the fact that relatives have another perspective being a relative and not a patient. For the goal 'quality of life', for example, it might be that at the time that the treatment stopped (the time point that the patient reported the achievement of goals) the quality of life of the patient was higher compared to the last phase of life. The latter might be the reference point of relatives when they reported whether the goal 'quality of life' was achieved; when we look at the negative aspects relatives mentioned, side effects and worsened quality of life are mentioned. It might also be that from the perspective of relatives it is very difficult seeing their loved one deteriorate and suffer and therefore more often report the goal 'quality of life' not achieved. It is known that relatives tend to assess a patient's quality of life as somewhat lower than the patient him or herself would do.^{19, 20}

Being satisfied with treatment decision goes together with negative feelings about treatment decision. Most of the relatives were, In hindsight, satisfied about the patients' choice to start treatment (78%), even if none of the goals were achieved (70%). These results are comparable to the patients' and oncologists view of making the right decision to start treatment (patients: 79% and 72% respectively; oncologists: 96% and 93% respectively) in the previous study of Mieras et al.¹⁰ It is known that measuring satisfaction is not without problems. It holds the risk of creating a positive bias which could for instance be related by the desire to give social desirable answers or, according to cognitive dissonance theory, a tendency to assess one's situation or actions as good in hindsight.^{21, 22} In any case, the fact that we found that over half of people who were satisfied with the treatment decision described negative aspects related to the decision taken shows that satisfaction does not cover the entire experience of the relatives. Most mentioned negative aspects were that the treatment did not work and that there were burdensome side effects of the treatment. These negative aspects should be taken into account when deciding to start a treatment with a relatively low chance on success and high chance on side effects e.g. by managing expectations of patients and relatives by clear communication and by attention for palliative or supportive care to treat side effects.

Next to negative aspects related to the treatment decision taken, many relatives also mentioned positive aspects. Most frequently it was mentioned that it was positive that they tried everything. Earlier we found that this was important for the patients and oncologists too.¹⁰ It was also important for many relatives that the patient's wish for treatment was followed, even when sometimes they thought themselves the treatment might have gone on for too long. It is noteworthy that none of the positive aspects we found really resonated with aspects valued at the end of life that were found in a study by Steinhauser et al. : 'pain and symptom management', 'clear decision making', 'preparation for death' and 'completion' valued at the end of life⁸. This might be related to the fact that in our study we focused on the evaluation of the decision to start systemic treatment. For patients who start with treatment and their families it might be more difficult to for example prepare for death than for people who do not start treatment. It might also be that they value this less.

Strengths and limitations

Strengths of this study are the perspective of the relative on the treatment for an incurable disease of their loved one, the contribution of both one academic and five non-academic hospitals, the large sample size of participants and the semi-structured interviews, so relatives were allowed to elucidate positive and negative aspects on the treatment satisfaction. A limitation is that the interview is on average about three months after the patient died and on average a bit more than half a year after the last gift of treatment the patient received, possibly giving recall bias.

Conclusion And Implications

Relatives reported patients' treatment goals as not achieved in a majority of the cases. They were, however, in majority of the cases satisfied about the treatment choice. Being satisfied does not provide a full picture of their experience with the treatment decision as a majority mentions negative aspects of this decision. At the time of making the treatment decision it is important to manage expectations about chance of success and possible side effects of the treatment. As relatives, like patients, find it important to do something, it can also be beneficial to not contrast the option of systemic treatment with the option of doing nothing. Palliative care can also be framed as a treatment option.

Declarations

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was approved by the medical ethical committee (METc) of the VU University Medical Centre in Amsterdam, the Netherlands (number NL57455.029.16). Both patients and relatives gave written consent to participate in the study.

AUTHOR' DISCLOSURE OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Adinda Mieras, Annemarie Becker, Roeline Pasman, Bregje Onwuteaka-Philipsen.

Provision of study materials or patients: Annemarie Becker-Commissaris, Lemke Pronk, Svitlana Tarasevych, Marian Tiemessen, Denise de Jong, Verina van Diepen

Collection and assembly of data: Adinda Mieras, Annemarie Becker, Roeline Pasman, Bregje Onwuteaka-Philipsen.

Data analysis and interpretation: Adinda Mieras, Annemarie Becker, Roeline Pasman, Bregje Onwuteaka-Philipsen.

Manuscript writing: All authors

Final approval of manuscript: All authors

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AVAILABILITY OF DATA AND MATERIALS

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Tables

Table 1. Demographic characteristics of study participants

Variable	N	%
Participants	118	100
Age - Years		
Mean \pm SD	62 \pm 11	
Range	30 - 85	
Sex		
Male	43	37
Female	75	63
Relation to patient		
Partner	96	81
Father/mother	1	1
Son/daughter	16	14
Sibling	4	3
Friend	1	1

Table 2. Explanations of being satisfied with the treatment choice.

	Total (n=118) N (%)	Satisfied (n=92) N (%)	Not satisfied* (n=26) N (%)
N column (%)			
Patients mentioned: **			
• Only positive aspects	47 (42)	42 (48)	5 (20)
• Positive and negative aspects	35 (31)	26 (30)	9 (36)
• Only negative aspects	31 (27)	19 (22)	11 (44)
Positive aspects mentioned			
• We tried everything	28 (24)	22 (24)	6 (23)
• It was the patients' choice	17 (14)	11 (12)	6 (23)
• Lived longer	16 (14)	15 (16)	1 (4)
• The treatment worked	14 (12)	11 (12)	3 (12)
• No side effects	12 (10)	10 (11)	2 (8)
• It gives hope	10 (8)	7 (8)	3 (12)
• Good quality of life	6 (5)	6 (7)	0 (0)
• Other	3 (3)	3 (3)	0 (0)
Negative aspects mentioned			
• The treatment didn't work	23 (19)	17 (18)	6 (23)
• Side effects	15 (13)	11 (12)	4 (15)
• It was not my choice	12 (10)	5 (5)	7 (27)
• Quality of life worsened	10 (8)	3 (3)	7 (27)
• Treatment was given too long	9 (8)	4 (4)	5 (19)
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• The treatment was started too late	4 (3)	4 (4)	0 (0)
Other aspects mentioned			
• Good quality of care	19 (16)	19 (21)	0 (0)
• Insufficient quality of care	15 (13)	9 (10)	6 (23)
• It was the choice of the oncologists	13 (11)	11 (12)	2 (8)
	7 (6)	3 (3)	4 (15)

- I don't know how it would have been otherwise
 - It helped science
- 3 (3) 3 (3) 0 (0)

*Including relatives who reported "not sure" on the treatment satisfaction. ** 4% missing. Percentages don't add up to 100% since more answers were possible.

Figures

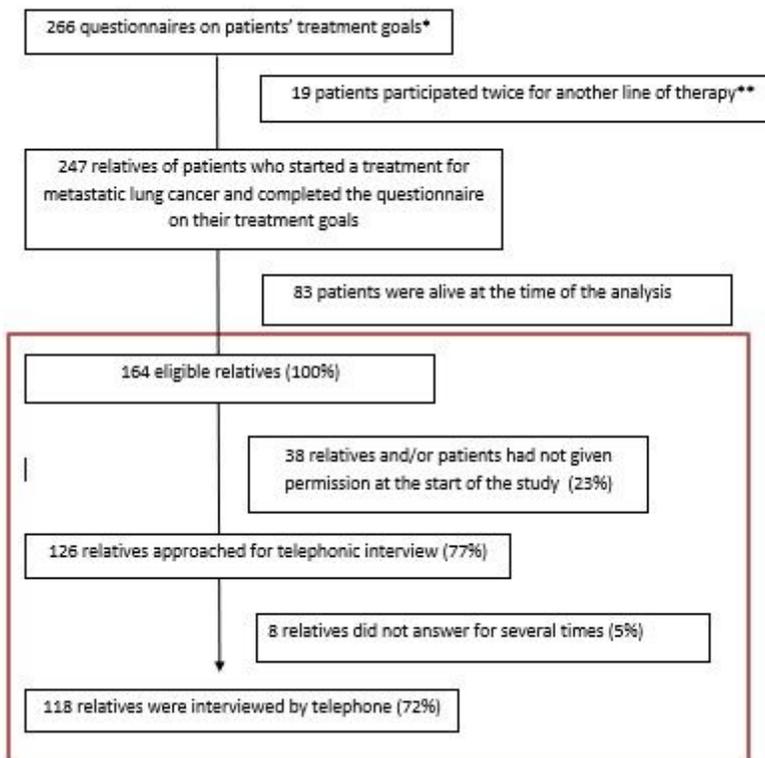


Figure 1

Flowchart. * consent from patient and relative was asked at the start of the treatment. ** Per patient relative was only called once

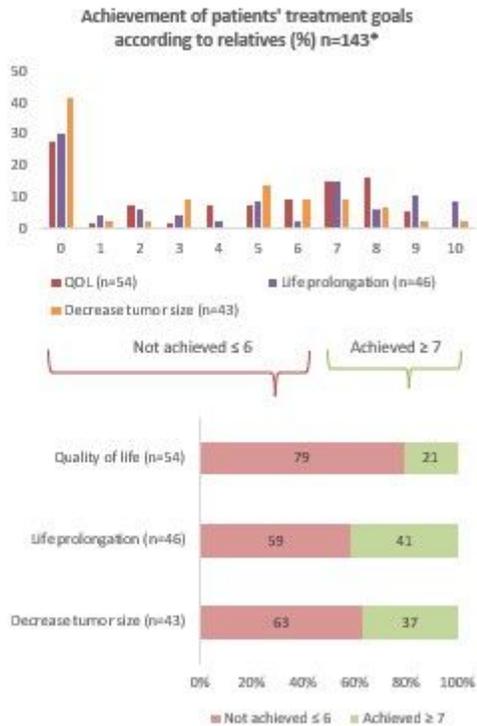


Figure 2

Achievement of the patients' treatment goals according to relatives. * Relatives (n=118) had answered on 143 treatment goals together.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Appendix.docx](#)