

# **Coping strategies of patients with advanced lung or colorectal cancer in six European countries: Insights from the ACTION study**

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*Under review*

## ABSTRACT

### Objective

Physical symptoms and psychological distress are common in patients with advanced cancer. Even when medical treatments are limited, supporting patients' adaptive coping strategies could potentially improve their quality of life. Developing such support would be aided by a greater understanding of patients' coping strategies and influencing factors. Thus, we examined the prevalence of various coping strategies and associated sociodemographic and clinical variables.

### Methods

We used sociodemographic and baseline data from the ACTION trial, including measures of Denial, Acceptance and Problem-focused coping (COPE and Brief COPE inventory), of patients with advanced cancer from six European countries. Healthcare professionals provided clinical background characteristics. Multilevel analyses were performed.

### Results

Data from 675 patients with stage III/ IV lung (342, 51%) or stage IV colorectal (333, 49%) cancer were used; mean age 66 (10 SD) years, 60% male. Overall, patients scored low on Denial and high on Acceptance and Problem-focused coping. Multivariate analysis showed that older patients scored higher on Denial than younger patients ( $\beta=0.05$ ; 95% CI 0.2 to 0.7), and patients from Italy ( $\beta=1.57$ ; 95% CI 0.76 to 2.39) and Denmark ( $\beta=1.81$ ; 95% CI 0.88 to 2.75) scored higher than patients in other countries. Higher educated patients scored higher on Acceptance than lower educated patients ( $\beta=0.05$ ; 95% CI 0.005 to 0.100). Patients with a WHO performance status of 1 ( $\beta=-0.75$ ; 95% CI -1.27 to -0.23) or 2 ( $\beta=-1.33$ ; 95% CI -2.33 to -0.34) scored higher on Problem-focused coping than patients with a WHO status of 0.

### Conclusion

Coping strategies of patients with advanced cancer appear to vary between subpopulations. We recommend taking these factors into account when developing tailored interventions to support patients' coping strategies.

## BACKGROUND

Being diagnosed with advanced, incurable cancer often disrupts patients' lives in diverse ways.<sup>1</sup> Patients can experience multiple physical symptoms and psychological distress.<sup>2,3</sup> When the disease has progressed to a point where curative treatments are unavailable, patients could particularly benefit from interventions aimed at improving their quality of life.<sup>4</sup>

One way of assisting patients in the last phase of their life is to support adaptive coping strategies. Coping strategies are defined as distinct, constantly changing cognitive, emotional and behavioral efforts to manage a (health) threat.<sup>5</sup> Patients can use a variety of coping strategies.<sup>6</sup> For instance, when using Denial, patients reduce the impact of their advanced disease by thinking that it is not real.<sup>6</sup> Acceptance, on the other hand, includes actively dealing with the advanced disease by accepting its reality<sup>7</sup> and managing feelings of distress.<sup>5</sup> Problem-focused coping extends this towards a behavioral approach, for example through taking actions to improve their way of living with their advanced disease.<sup>6</sup> The use of coping strategies can vary between patients, situations and over time.<sup>6</sup> Different coping strategies may be used simultaneously or alternately.<sup>8</sup> Whether a certain coping strategy is beneficial or not is highly dependent on the individual patient and situational context.<sup>6,7,9</sup>

Evidently, the way patients cope with their advanced disease has an impact on their physical and psychological well-being.<sup>10</sup> Since coping strategies are modifiable,<sup>6</sup> supporting and encouraging adaptive coping strategies can contribute to the well-being of patients, also when their disease has reached an advanced, incurable stage.<sup>11</sup> Therefore, coping support is increasingly incorporated into interventions for patients with advanced cancer.<sup>12-14</sup> Coping strategies can also be used to tailor interventions. For instance, a pain management program for community dwelling older people was more successful in reducing pain and symptoms of anxiety when the intervention was tailored to the patients' specific coping strategy, as compared to generic and untailored interventions.<sup>15</sup>

The relevance of assessing and responding to coping needs throughout the disease trajectory of patients has been confirmed and recognized by numerous professional organizations, such as the American Society of Clinical Oncology<sup>16</sup> and the National Institute for Clinical Excellence in the United Kingdom.<sup>17</sup> Research in this area has mainly focused on patients in earlier stages of cancer.<sup>18-20</sup> It is unclear if the findings in these patients are generalizable to patients with advanced cancer who face specific challenges, such as preparatory grief,<sup>21</sup> death anxiety<sup>22</sup> and increased existential distress.<sup>23</sup> Given the importance of the sociocultural context for the appraisal of a (health) threat, it is not surprising that coping strategies have been found to differ across age groups,<sup>24</sup> diseases,<sup>8</sup> and cultures.<sup>25,26</sup> It is however unknown to what extent sociodemographic and clinical variables influence the coping strategies of patients with advanced cancer. Detailed insights into coping strategies of patients with advanced cancer can inform the design of interventions delivering coping support, and the evaluation and improvement of existing interventions by tailoring them to patients' individual coping strategies. We aimed to (1) characterize the prevalence of the coping strategies Denial, Acceptance and Problem-focused coping among patients with advanced lung or

colorectal cancer and (2) identify sociodemographic and clinical characteristics associated with the use of these coping strategies, including a comparison between countries.

## METHODS

### Participants

We used the sociodemographic and baseline data of patients included in the care-as-usual arm of the international ACTION trial, a cluster randomized trial investigating the effects of an advance care planning intervention as compared to care as usual. The patients were recruited in outpatient pulmonology and oncology departments in academic and non-academic hospitals in Belgium, Denmark, Italy, the Netherlands, Slovenia and the United Kingdom, between June 2015 and May 2017 (see Box 1 for the inclusion and exclusion criteria). The ACTION study has been described in more detail elsewhere.<sup>27</sup> Written informed consent was obtained. Research ethics committees of the participating countries approved the trial. The trial is registered in the 'international standard randomised controlled trial number' registry (ISRCTN63110516).

**Box 1.** Inclusion and exclusion criteria for the ACTION trial.

Inclusion criteria:

1. Histologically confirmed diagnosis of:
  - a. Lung cancer:
    - Small cell – extensive disease/ Stage III or IV\*
    - Non-small cell – stage III or IV\*
  - b. Colorectal cancer: Stage IV or metachronous metastases\*,  
\*according to the 7th edition of TNM classification and staging system
2. Written informed consent to participate,
3. WHO performance status of 0-3.

Exclusion criteria:

1. Age <18 years,
2. Unable to provide consent,
3. Unable to complete questionnaire in country's language,
4. Less than 3 months anticipated life expectancy,
5. Taking part in a research study that is evaluating palliative care services or communication strategies.

### Measures

#### *Sociodemographic and clinical variables*

Patients provided information about their age, educational level, gender, living situation and religion. Their healthcare providers provided information on the type and stage of the disease and the time since diagnosis of both the primary tumor and the current stage of the disease. Additionally, they gave information on which treatment patients received and their WHO performance status, ranging from 0 to 3.<sup>28</sup>

## Coping

We measured patients' coping strategies with the subscales Denial and Acceptance of the COPE Inventory and the subscales Planning and Active coping of the Brief COPE.<sup>7,29</sup> Patients were asked to rate the items according to the best description of how they had been coping with their disease during the past two months. Items were rated on a four point Likert scale, ranging from 1 ("I don't do this at all"), 2 ("I do this a little bit"), 3 ("I do this a medium amount") to 4 ("I do this a lot").

Following questionnaire instructions, we confirmed the subscales of the underlying coping strategies,<sup>7</sup> by conducting a principal components analysis with the twelve selected items of the COPE Inventory and Brief COPE. The analysis identified three distinct factors, each with eigenvalues above 1. The analysis confirmed the subscales Denial (explained variance 29%) and Acceptance (explained variance 14%), which were also described by the developers of the COPE Inventory.<sup>7</sup> The analysis also showed that the subscale Active coping and the subscale Planning of the Brief COPE loaded on the same factor (explained variance 23%), which is in accordance with the structure of the questionnaire as described by the developers.<sup>29</sup> We therefore combined Active coping and Planning, and, following previous research,<sup>30</sup> labelled the resulting subscale as Problem-focused coping (see Box 2 for an overview of the identified subscales and included questions). We subsequently summed the responses per subscale to create subscale scores. This resulted in a range of 4 to 16 for each subscale. Higher scores indicate more use of that particular coping strategy.

**Box 2.** Overview of the subscales and items of the COPE and Brief COPE after the principal component analysis.

Denial:

- (1) I act as though this hasn't even happened.
- (2) I say to myself "this isn't real".
- (3) I pretend that this hasn't really happened to me.
- (4) I refuse to believe that this happened to me.

Acceptance:

- (1) I accept the reality of the fact that this has happened to me.
- (2) I learn to live with my situation.
- (3) I get used to the idea that this has happened to me.
- (4) I accept that this has happened to me and that it can't be changed.

Problem-focused coping

- (1) I concentrate my efforts on doing something about my situation.
- (2) I take action to try to make my situation better.
- (3) I try to come up with a strategy about what to do in my situation.
- (4) I think hard about what steps to take in my situation.

## Statistical methods

Missing items are common in palliative care trials.<sup>31</sup> Given the low percentage of missing items (<5%) in our study, we carried out a complete case analysis by including only the data of patients with full responses on all items of the three respective coping subscales.

We used the Statistical Package for the Social Sciences version 24 (SPSS, Chicago, IL) for the analyses. We summarized patients' sociodemographic and clinical characteristics with means and standard deviations for the continuous variables and counts and percentages for the categorical variables. The distribution of scores on the coping subscales is presented with mean sum scores and standard deviations. We calculated Pearson correlation coefficients to assess the linear correlation between the coping strategies.

A multivariate multilevel regression model was used to analyze associations between coping strategies and sociodemographic and clinical variables. This type of model allows accounting for clustering at the hospital level and thus for non-independency of observations.<sup>32</sup> First, univariate multilevel models were used to test associations between sociodemographic and clinical variables and distinct coping strategies. A significance level of  $p < 0.20$  was used to select variables for the final model. For the final multivariate model, the significance level was set at  $p < 0.05$ . Betas, 95% confidence intervals and  $p$ -values are reported.

## RESULTS

### Descriptive statistics

The analyses included 675 patients who were enrolled in the control arm of the ACTION trial. Numbers of patients per country ranged from  $n=25$  (Slovenia) to  $n=168$  (the Netherlands). Sociodemographic and clinical characteristics are shown in Table 1. Patients' average age was 66 (SD 9.6) years and the majority of patients were male (60%). Most of the patients were living with a partner (76%) and had children (87%). About half of the patients described themselves as being religious (52%). The majority of patients were diagnosed with lung cancer stage III or IV (51%). On average, patients were diagnosed with their primary tumor 1.7 years earlier (2.4 SD). At the time of inclusion, most patients received systemic antitumor treatment (92%).

### Prevalence of coping strategies

655 patients were included in the analysis of Denial; this number was 659 for Acceptance and 643 for Problem-focused coping. On average, patients scored low on the use of Denial (mean sum score 6.6 (SD 3.1) and high on Acceptance and Problem-focused coping (mean sum score 12.6 (SD 2.7) and 12.2 (SD 2.9), respectively; Table 2). Higher scores on Acceptance were correlated with higher scores on Problem-focused coping ( $r=0.36$ ;  $p < 0.001$ ) and higher scores on Problem-focused coping were correlated with higher scores on Denial ( $r=0.11$ ;  $p < 0.001$ ). The use of Denial and Acceptance was not correlated ( $r=0.04$ ;  $p=0.27$ ).

**Table 1.** Sociodemographic and Clinical Characteristics per Country

	Belgium (n = 135)	Denmark (n = 68)	Italy (n = 139)	Netherlands (n = 168)	Slovenia (n = 25)	United Kingdom (n = 140)	Total (N = 675)
Age in years, mean (SD)	65.3 (9.5)	65.5 (9.0)	65.5 (9.6)	65.4 (8.1)	71.1 (9.5)	68.4 (11.0)	66.2 (9.6)
Years of education, mean (SD)	13.9 (4.4)	13.5 (5.9)	11.4 (5.2)	13.2 (3.7)	9.9 (3.3)	13.5 (4.7)	12.9 (4.7)
Gender (male), n (%)	91 (67.4)	35 (51.5)	90 (64.7)	111 (66.1)	10 (40.0)	70 (50.4)	407 (60.4)
Living with a spouse, n (%)	106 (79.1)	55 (80.9)	99 (73.9)	129 (78.2)	15 (62.5)	93 (69.9)	497 (75.5)
Having children, n (%)	114 (85.1)	62 (91.2)	118 (86.8)	146 (86.9)	21 (84.0)	60 (44.1)	583 (87.3)
Religion, n (%)							
Prefers not to specify	31 (23.8)	9 (13.6)	16 (11.7)	17 (10.1)	2 (8.0)	18 (13.2)	93 (14.0)
Not religious	30 (23.1)	38 (57.6)	24 (17.5)	76 (45.2)	2 (8.0)	58 (42.6)	228 (34.4)
Religious	69 (53.1)	19 (28.8)	97 (70.8)	75 (44.6)	21 (84.0)	60 (44.1)	341 (51.5)
Diagnosis, n (%)							
Lung cancer, stage III or IV	79 (58.5)	34 (50.0)	71 (51.1)	76 (45.2)	0 (0.0)	82 (58.6)	342 (50.7)
Colorectal cancer, stage IV	56 (41.5)	34 (50.0)	68 (48.9)	92 (54.8)	25 (100)	58 (41.4)	333 (49.3)
Years since diagnosis, mean (SD)	1.5 (1.7)	2.7 (3.2)	2.0 (3.5)	1.9 (1.9)	2.3 (2.4)	0.9 (1.4)	1.7 (2.4)
Years since diagnosis of current stage, mean (SD)	1.1 (1.4)	1.6 (2.2)	0.8 (1.1)	1.2 (1.4)	1.3 (1.9)	0.4 (0.7)	1.0 (1.4)
Current systemic antitumor treatment, <sup>1</sup> n (%)	126 (96.2)	68 (100.0)	135 (97.1)	144 (86.2)	8 (53.3)	115 (87.8)	596 (91.6)
WHO performance status, <sup>2</sup> n (%)							
3	0 (0.0)	0 (0.0)	0 (0.0)	2 (1.2)	1 (4.0)	5 (3.6)	8 (1.2)
2	7 (5.5)	1 (1.5)	2 (1.4)	12 (7.1)	13 (52.0)	20 (14.3)	55 (8.3)
1	56 (44.1)	40 (58.8)	65 (47.1)	122 (72.6)	10 (40.0)	49 (35.0)	342 (51.4)
0	64 (50.4)	27 (39.7)	71 (51.4)	32 (19.0)	1 (4.0)	66 (47.1)	261 (39.2)

NOTE:

<sup>1</sup> Includes chemotherapy, immunotherapy and targeted therapy.<sup>2</sup> 0-Fully active, able to carry on all pre-disease performance without restriction, 1-Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light house work, office work, 2-Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours, 3-Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.

Missings total: Age (n=6), Education (n=89), Gender (n=1), Living with a spouse (n=15), Having children (n=6), Religion (n=13), Years since diagnosis (n=1), Years since diagnosis of current stage (n=6), Systemic treatment (n=24), WHO performance status (n=9)

## Multilevel model: Associations between coping strategies and sociodemographic and clinical variables

### *Associations between Denial and sociodemographic and clinical variables*

For Denial, the univariate multilevel models showed significant associations ( $p < 0.20$ ) with age, years of education, having children, years since the diagnosis of the primary tumor and country of residence (S-Table 1). These variables were included in the final multivariate model. That multivariate multilevel model (Table 3) showed that older patients scored higher on Denial than younger patients ( $\beta = 0.05$ ; 95% CI, 0.2 to 0.7,  $p < 0.001$ ) and that patients in Italy ( $\beta = 1.57$ ; 95% CI, 0.76 to 2.39;  $p < 0.001$ ) and Denmark ( $\beta = 1.81$ ; 95% CI, 0.88 to 2.75;  $p < 0.001$ ) scored higher on Denial than patients in other countries.

**Table 2.** Patients Mean Sum Scores (SD) on each coping subscale by sociodemographic and clinical characteristic and country of residence

	Denial <sup>1</sup> (n=655)	Acceptance <sup>1</sup> (n=659)	Problem-focused <sup>1</sup> (n=643)
Patient Mean Sum Score (SD)	6.6 (3.1)	12.6 (2.7)	12.2 (2.9)
Age in years			
18-64	6.1 (2.8)	12.6 (2.9)	12.6 (2.7)
65-79	6.9 (3.2)	12.6 (2.5)	12.0 (2.8)
≥80	7.3 (3.9)	13.3 (3.0)	11.5 (3.6)
Years of education			
0-4	6.4 (2.8)	12.5 (2.2)	10.4 (3.3)
5-12	7.0 (3.3)	12.3 (2.8)	12.2 (2.8)
≥13	6.1 (2.8)	12.9 (2.5)	12.3 (2.9)
Gender			
Male	6.6 (3.1)	12.5 (2.7)	12.0 (3.0)
Female	6.6 (3.2)	12.8 (2.8)	12.6 (2.7)
Living with a spouse			
Yes	6.6 (3.0)	12.6 (2.7)	12.2 (2.8)
No	6.7 (3.5)	12.6 (2.6)	12.1 (3.1)
Having children			
Yes	6.7 (3.2)	12.6 (2.7)	12.2 (2.9)
No	5.8 (2.5)	12.8 (2.7)	12.4 (2.9)
Religion			
Prefers not to specify	6.5 (3.0)	12.0 (2.9)	11.7 (3.0)
Not religious	6.3 (3.1)	12.7 (2.7)	12.2 (2.9)
Religious	6.9 (3.1)	12.7 (2.6)	12.5 (2.8)
Diagnosis			
Lung cancer, stage III or IV	6.7 (3.1)	12.4 (2.6)	12.1 (2.8)
Colorectal cancer, stage IV	6.6 (3.1)	12.8 (2.8)	12.3 (3.0)
Years since diagnosis			
≤1 year	6.5 (3.0)	12.7 (2.7)	12.3 (2.8)
> 1 year	6.5 (3.1)	12.8 (2.8)	12.4 (3.1)
Years since diagnosis of current stage			
≤0.5 year	6.5 (3.0)	12.6 (2.6)	12.4 (2.6)
>0.5 year	6.7 (3.3)	12.7 (2.7)	12.0 (3.1)
Current systemic treatment <sup>2</sup>	6.6 (3.1)	12.6 (2.6)	12.2 (2.8)
WHO performance status <sup>3</sup>			
3	5.8 (2.4)	13.4 (2.1)	11.3 (1.9)
2	7.2 (3.6)	12.5 (2.8)	11.8 (2.9)
1	6.6 (3.1)	12.3 (2.7)	12.2 (2.8)
0	6.6 (3.0)	12.9 (2.7)	12.4 (3.1)
Country of residence			
Belgium (n=135)	6.5 (2.9)	11.7 (2.8)	10.4 (3.0)
Denmark (n=68)	7.6 (3.5)	13.3 (2.4)	12.6 (2.9)
Italy (n=138)	7.5 (3.1)	12.5 (2.5)	12.8 (2.3)



**Table 2.** Patients Mean Sum Scores (SD) on each coping subscale by sociodemographic and clinical characteristic and country of residence (continued)

	Denial <sup>1</sup> (n=655)	Acceptance <sup>1</sup> (n=659)	Problem-focused <sup>1</sup> (n=643)
Netherlands (n=166)	6.0 (2.9)	12.5 (2.6)	13.0 (2.4)
Slovenia (n=25)	7.3 (3.5)	12.6 (2.5)	12.4 (2.6)
United Kingdom (n=139)	6.1 (3.0)	13.4 (2.8)	12.2 (3.2)

NOTE:

<sup>1</sup> The range for the coping strategies is 4 to 16. A higher score on the subscale indicates a greater use of the particular coping strategy.<sup>2</sup> Includes chemotherapy, immunotherapy, and targeted therapy.<sup>3</sup> 0-Fully active, able to carry on all pre-disease performance without restriction, 1-Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light house work, office work, 2-Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours, 3-Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.

Missing range: Age (5-6), Education (n=79-89), Gender (n=1), Living with a spouse (n=14-15), Children (n=6-), Religion (n=12-13), Time since diagnosis (n=1), Time since diagnosis of current stage (n=6), Systemic treatment (n=20-23), WHO performance status (n=8-9)

**Table 3.** Multivariate multilevel analysis of the coping strategy Denial (n=655)

	$\beta$	95% CI	<i>p</i>
Explanatory Variables			
Age in years	.05	.02, .07	<.001*
Years of education	-.04	-.10, .01	.129
Having children			.074
Yes	.67	-.07, 1.41	
No	Ref		
Years since diagnosis	.04	-.06, .14	.418
Country of residence			<.001*
Netherlands	.08	-.66, .82	.831
Belgium	.69	-.11, 1.49	.090
Slovenia	1.07	-.36, 2.50	.141
Italy	1.57	.76, 2.39	<.001
Denmark	1.81	.88, 2.75	<.001
United Kingdom	Ref		

\*  $p < 0.05$ , and thus significant

### Associations between Acceptance and sociodemographic and clinical variables

The univariate multilevel models for Acceptance showed significant associations ( $p < 0.20$ ) with years of education, being religious or not, primary diagnosis, years since the diagnosis of the primary tumor and diagnosis of the current stage, WHO performance status and country of residence (S-Table 1). These variables were included in the final multivariate model. The multivariate multilevel model (Table 4) showed that patients with higher education scored higher on Acceptance than patients with lower education ( $\beta = 0.05$ ; 95% CI 0.005 to 0.100;  $p = 0.030$ ).

**Table 4.** Multivariate multilevel analysis of the coping strategy Acceptance (n=659)

	$\beta$	95% CI	p
<b>Explanatory Variables</b>			
Years of education	.05	.005, .100	.030*
Religion			.277
Prefers not to specify	-.55	-1.23, .13	
No	-.08	-.58, .42	
Yes	Ref		
Diagnosis			.463
Lung cancer, stage III or IV	-.18	-.67, .30	
Colorectal cancer, stage IV	Ref		
Years since diagnosis	.02	-.09, .12	.758
Years since diagnosis of current stage	.16	-.03, .34	.100
WHO performance status <sup>1</sup>			.075
3	.88	-1.26, 3.02	
2	-.54	-1.52, .44	
1	-.59	-1.09, -.09	
0	Ref		
Country of residence			.060
Netherlands	-.84	-1.90, .21	
Belgium	-1.88	-2.99, -.77	
Slovenia	-.80	-2.33, .74	
Italy	-.66	-1.77, .45	
Denmark	-.19	-1.56, 1.19	
United Kingdom	Ref		

\*  $p < 0.05$ , and thus significant

<sup>1</sup> 0-Fully active, able to carry on all pre-disease performance without restriction, 1-Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light house work, office work, 2-Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours, 3-Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.

### ***Associations between Problem-focused coping and sociodemographic and clinical variables***

For Problem-focused coping, the univariate multilevel models showed significant associations ( $p < 0.20$ ) with age, years of education, gender, being religious or not, years since the diagnosis of the primary tumor, WHO performance status and country of residence (S-Table 1). These variables were included in the final multivariate model. This model (Table 5) showed that patients with a WHO status of 1 ( $\beta = -0.75$ ; 95% CI -1.27 to -0.23;  $p = 0.005$ ) or 2 ( $\beta = -1.33$ ; -2.33 to -0.34 95% CI,  $p = 0.009$ , i.e. patients who were somewhat restricted in their activities and selfcare) scored lower on Problem-focused coping than patients with a WHO status of 0 (i.e. patients who were fully active).

**Table 5.** Multivariate multilevel analysis of the Problem-focused coping strategy(n=643)

	$\beta$	95% CI	P
Explanatory Variables			
Age in years	-.02	-.04, .01	.222
Years of education	.04	-.01, .09	.135
Gender			.187
Male	-.32	-.81, .16	
Female	Ref		
Religion			.272
Prefers not to specify	-.39	-1.10, .33	
No	-.40	-.93, .13	
Yes	Ref		
Years since diagnosis	-.01	-.11, .08	.772
WHO performance status <sup>1</sup>			.009*
3	-1.54	-3.82, .73	.183
2	-1.33	-2.33, -.34	.009*
1	-.75	-1.27, -.23	.005*
0	Ref		
Country of residence			.086
Netherlands	1.28	-.56, 3.12	
Belgium	-1.68	-3.68, .32	
Slovenia	.80	-1.66, 3.25	
Italy	.52	-1.48, 2.52	
Denmark	.53	-1.94, 3.00	
United Kingdom	Ref		

\*  $p < 0.05$ , and thus significant

<sup>1</sup> 0-Fully active, able to carry on all pre-disease performance without restriction, 1-Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light house work, office work, 2-Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours, 3-Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.

## CONCLUSIONS

We found that patients with advanced lung or colorectal cancer predominantly use Acceptance and Problem-focused coping. Coping strategies used by patients with advanced cancer appear to be influenced by age, level of education, WHO status and country of origin.

### Prevalence of coping strategies

Our finding that patients scored low on Denial and higher on Acceptance and Problem-focused coping aligns with observations in patients with early stage cancer,<sup>33</sup> patients who were recently diagnosed with incurable cancer<sup>34</sup> and cancer survivors.<sup>35</sup>

Our results also show that coping strategies were correlated: higher scores on Acceptance were correlated with higher scores on Problem-focused coping. Endler and colleagues observed that

patients with acute health problems predominantly used one coping strategy, in an effort to soothe their symptoms.<sup>8</sup> Contrarily, patients with chronic health problems relied on more than one coping strategy, possibly because they have to adjust their life styles to a new situation.<sup>8</sup> A similar challenge might apply to the situation of patients with advanced cancer. The seemingly contradictory coping strategies Denial and Problem-focused coping were also positively correlated, be it only weakly. Problem-focused coping includes taking action to make a situation better.<sup>6</sup> Possibly, this mechanism is also used as a means to distract oneself from the actual situation.

### **Associations between coping strategies and sociodemographic and clinical variables**

We identified different patterns in the use of coping strategies across various subpopulations. Older patients scored higher on Denial than their younger counterparts. The same finding has been observed in patients with lung cancer.<sup>36</sup> It has been hypothesized that older patients use 'threat minimization' more often, which includes keeping feelings to oneself and avoiding emotional distress by trying to forget.<sup>37</sup> We also found that patients with higher education scored higher on Acceptance. Patients with higher education might have higher cognitive abilities and therefore be more able to manage the multiple demands of a terminal illness. Higher education has also been found to be related to increased prognostic awareness<sup>38</sup> and more communication and involvement in end-of-life decision-making.<sup>39</sup> Possibly, having better abilities in managing the multiple demands of a terminal illness and better involvement in the decision-making contribute to the use of Acceptance.

We also found that patients with a worse WHO performance status scored lower on Problem-focused coping than patients who were fully active and did not experience restrictions. The behavioral efforts that are linked to Problem-focused coping might become more challenging when patients' physical abilities decline.

Patients in Italy and Denmark scored higher on Denial than patients in other countries. A review about culture and end of life care demonstrated that patients in Italy and Norway (a Scandinavian country with supposedly shared values and cultural resemblance to Denmark) showed a general reluctance to talk about death, as well as a trend towards partial or no disclosure of patients' diagnosis and prognosis.<sup>40</sup> This was related to respect for privacy and/ or to a strong death taboo.<sup>40</sup> Not disclosing a diagnosis and a general taboo to talk about death could facilitate the use of Denial, which entails thinking that the disease is not real. Denial itself has been found to be related to both negative and positive outcomes. One study showed that patients with asthma who scored high on Denial tended to disregard symptoms of breathing difficulty, resulting in a higher rate of hospitalizations.<sup>41</sup> Yet, in another study with patients with lung cancer high scores on denial were related to a better overall perception of health and less pain.<sup>9</sup>

## Implications for clinical practice

The results of our study can inform healthcare providers about individual differences in the use of coping strategies. As Walshe and colleagues stressed,<sup>14</sup> a major conceptual issue in current interventions is that they largely ignore the coping strategies of patients with advanced cancer, which might worsen their psychological experience.<sup>14</sup> Our results might be used to start discussions of how to support patients with different coping strategies. Next to tailoring interventions accordingly, our findings may help to design interventions on coping support and to decide which elements of coping to include. In a trial investigating coping support as an element of a palliative care intervention for patients with advanced cancer, the coping support included for instance the improvement of behavioral strategies.<sup>11</sup> Ultimately, patients' quality of life improved when coping was addressed more often.<sup>11</sup> Interestingly, clinicians highlighted behavioral coping strategies less and counseling more throughout the intervention.<sup>11</sup>

Based on our results we advise to take the tendency of older patients to use Denial into account, as well as patients' health status. Targeted coping support considering patients' individual coping strategies has the potential to be more efficient in improving patient outcomes. Using information on patients' coping strategies could be extended towards information provision or psychoeducation on, for example, pain control. Since it has been suggested that healthcare providers often lack the appropriate skills to assess patients' coping strategies, psychologists could support them in diagnosing and integrating the information into daily care where needed.<sup>17,42</sup>

## Strengths

This paper presents unique data of patients who suffer from an advanced stage of one of two common types of cancer types in six European countries. We were able to collect detailed sociodemographic and clinical information, which allowed a thorough analysis of self-reported coping strategies.

## Limitations

To minimize questionnaire burden, we restricted the assessment of coping strategies to three subscales. Future research should include additional coping strategies, such as the use of spirituality or seeking social support. This might give more information about cultural sensitivity and relevance of coping strategies in different countries. Besides, since we observed patients using a combination of coping strategies, future research should investigate to what extent combinations of coping strategies are beneficial for patients.

## Conclusion

We investigated the prevalence of coping strategies and associated sociodemographic and clinical characteristics in patients with advanced cancer in six European countries. We found that patients with advanced cancer predominantly use Acceptance and Problem-focused coping and also use different strategies simultaneously. Denial was used less often. Being aware of the variance in the use

of coping strategies can help healthcare professionals to coordinate and finetune their care more efficiently. Further, the design and implementation of interventions should be tailored to patients' coping strategies.

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## SUPPLEMENTARY MATERIAL

**S-Table 1.** Univariate multilevel analysis of the association between sociodemographic characteristics, clinical characteristics and country of residence, and coping strategies (online only)

	Denial (n=655)			Acceptance (n=659)			Problem-focused (n=643)		
	$\beta$	95% CI	$p$	$\beta$	95% CI	$p$	$\beta$	95% CI	$p$
Sociodemographic Characteristic									
Age in years	.05	.03, .08	<.001*	-.00	-.02, .02	.807	-.03	-.05, -.01	.007*
Years of education	-.06	-.12, -.01	.021*	.06	.01, .11	.010*	.05	.00, .10	.057*
Gender			.845			.434			.024*
Male	.05	-.44, .54		-.17	-.58, .25		-.50	-.93, -.06	
Female	Ref			Ref			Ref		
Living with a spouse			.503			.740			.548
Yes	-.19	-.74, .36		.08	-.39, .56		.15	-.35, .65	
No	Ref			Ref			Ref		
Having children			.011*			.462			.480
Yes	.92	.21, 1.63		-.23	-.83, .38		-.23	-.87, .41	
No	Ref			Ref			Ref		
Religion			.344			.153*			.101*
Prefers not to specify	-.27	-.99, .46		-.61	-1.24, .01		-.49	-1.15, .16	
Not religious	-.40	-.94, .15		-.20	-.67, .27		-.48	-.96, .01	
Religious	Ref			Ref			Ref		
Clinical Characteristic									
Diagnosis			.535			.092*			.822
Lung cancer, stage III or IV	.15	-.33, .64		-.36	-.77, .06		-.05	-.49, .39	
Colorectal cancer, stage IV	Ref			Ref			Ref		
Years since diagnosis	.08	-.02, .18	-.106*	.08	-.00, .17	.060*	.08	.00, .17	.061*
Years since diagnosis of current stage	.08	-.09, .25	.374	.20	.05, .34	.009*	-.03	-.18, .13	.750
Systemic treatment <sup>1</sup>			.751			.374			.484
Yes	.14	-.74, 1.03		.36	-.43, 1.14		-.29	-.52, 1.10	
No	Ref			Ref			Ref		
WHO performance status <sup>2</sup>			.245			.043*			.012*
3	-.23	-2.42, 1.96		-.16	-2.03, 1.71		-1.66	-3.72, .40	
2	.99	.02, 1.96		-.65	-1.50, 1.90		-.92	-1.80, -.05	
1	.15	-.38, .67		-.63	-1.08, -1.83		-.70	-1.17, -.23	
0	Ref			Ref			Ref		
Country of residence			<.001*			.098*			.044*
Netherlands	-.12	-.81, .58		-.95	-2.13, .24		.88	-.55, 2.30	
Belgium	.43	-.31, 1.16		-1.83	-3.10, -.56		-1.73	-3.28, -.19	
Slovenia	1.24	-.07, 2.55		-.82	-2.43, .79		.23	-1.69, 2.14	
Italy	1.40	.67, 2.13		-.95	-2.22, .32		.62	-.92, 2.17	
Denmark	1.49	.59, 2.38		-.15	-1.71, 1.40		.45	-1.45, 2.34	
United Kingdom	Ref			Ref			Ref		

\*  $p < 0.20$ , and thus included in the final model.<sup>1</sup> Includes chemotherapy, immunotherapy, and targeted therapy.<sup>2</sup> 0-Fully active, able to carry on all pre-disease performance without restriction, 1-Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light house work, office work, 2-Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours, 3-Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.