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## **Information needs of older patients newly diagnosed with cancer**

*M.E. Hamaker, I.C. van Walree, P.A.L (Nelleke) Seghers, F. van den Bos, P. Soubeyran, S. O'Hanlon, S. Rostoft*

Marije E. Hamaker, MD PhD, department of geriatric medicine, Diaconessenhuis Utrecht the Netherlands

Inez C. van Walree, MD PhD, department of geriatric medicine, Jeroen Bosch Ziekenhuis, Den Bosch, the Netherlands

P.A.L.(Nelleke) Seghers, MD, department of geriatric medicine, Diaconessenhuis, Utrecht, the Netherlands

Frederiek van den Bos, MD PhD, department of internal medicine, Leiden University Medical Centre, Leiden, the Netherlands

Pierre Soubeyran, MD PhD, department of oncology, Institut Bergonié, Université de Bordeaux, Bordeaux, France

Shane O'Hanlon, MB, department of geriatric medicine, St Vincent's University Hospital and University College Dublin, Dublin, Ireland

Siri Rostoft, MD PhD, department of geriatric, Oslo University Hospital, Oslo, Norway; Institute of Clinical Medicine, University of Oslo, Oslo, Norway.

### *Corresponding author:*

Marije E. Hamaker, MD PhD  
Diaconessenhuis, department of geriatric medicine  
Bosboomstraat 1  
3572 KE Utrecht  
The Netherlands

Email: [mhamaker@diakhuis.nl](mailto:mhamaker@diakhuis.nl)

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## **Abstract**

### *Background*

Understanding what information patients want and need is an important step in optimizing care. Therefore, we set out to collect all available evidence about the information that is most important to older patients with a new cancer diagnosis and whether or not these information needs are sufficiently addressed.

### *Method*

A systematic literature review of Embase and Medline.

### *Results*

We included eighteen studies addressing the importance of a range of information topics and studies addressing the sufficiency of information provided. On a scale from 1-10, patients ranked information about prognosis and the chance of cure as the most important category (median ranking 10, interquartile range (IQR) 8-10), followed by information on cancer itself (median 9, IQR 5.5-9), and treatment options (median 8, IQR 8-9). Information on side-effects of treatment (median 7, IQR 6-8), and practicalities (median 6, IQR 5-7.5) were also considered important. Patients rated information about the practicalities of treatment as the most insufficiently addressed (median 9.5), followed by self-care at home (median 9), and information about prognosis and side-effects (median 8 for both).

### *Conclusion*

This systematic review demonstrates that information provision about the cancer itself and about treatment options is generally satisfactory to patients, while information about prognosis, practicalities of treatment and self-care at home could be improved. However, there is significant heterogeneity among older patients regarding which information is most important to them, thus requiring an ongoing dialogue between patients and health care providers about which information is most needed at any given time.

## **Introduction**

For most patients, being diagnosed with cancer is a stressful life-event, likely to turn their world upside down. The diagnosis is often perceived as potentially life-threatening, and may cause significant physical and psychological distress due to the disease itself and/or its treatment.<sup>1</sup> Health care professionals play an important role in assisting patients as they go through this process.

For cancer patients, having timely access to desired information improves involvement in the decision-making process, induces greater satisfaction with treatment choices, and increases feelings of control over their life and illness.<sup>1,2</sup> In fact, information seeking is a key strategy used by many cancer patients to cope with stress,<sup>2</sup> and being adequately informed was shown to improve a patients' ability to cope during different phases of the cancer care trajectory.<sup>1</sup> Ensuring that patients are provided with the appropriate information is not only ethically sound but also good medical practice.<sup>3</sup> Studies show that when patients understand more about their illness and treatment, this improves quality of life, decreases health care consumption, and results in better compliance, increased ability to function on a day-to-day basis with the disease, and decreased anxiety and depression.<sup>3,4</sup>

However, information about cancer and its treatment can be overwhelming, both in amount and complexity. In fact, research has repeatedly shown that cancer patients' recall of medical information is poor, as they forget about 40–80% of information provided by health care providers.<sup>5,6</sup> This means that information provision needs careful tailoring. On the one hand, health care providers need to ensure that the individual patient receives and remembers the information that is most important for their understanding and coping. On the other hand, patients also need to receive the information deemed necessary within the shared decision making and informed consent process.

This systematic review was performed as part of GerOnTe, which is an international project aiming to improve the care pathway for older patients with cancer. Understanding what information older patients want and need is an important step in optimizing care, and therefore, we set out to collect all available studies assessing which information is most important to older patients with a new cancer diagnosis and whether or not these information needs are sufficiently addressed.

## **Methods**

This study was funded through an unrestricted grant by the European Union (project number: 945218).

### *Search strategy and article selection*

The following search was performed on January 13<sup>th</sup> 2021, in both Medline and Embase: (communication[tiab] OR information[tiab] OR (decision[tiab] AND making[tiab])) AND needs[tiab] and (cancer[tiab] OR oncology[tiab] OR malign\*[tiab]). Tiab refers to title and abstract. We used standard search filters to limit the search to studies published from 2000 onward, and to patients aged 65 years and older.

The titles and abstracts of all studies retrieved by the search were assessed by one reviewer (MH) to determine which warranted further examination. All potentially relevant articles were subsequently screened as full text by two authors (MH and IvW). We differentiated between studies addressing the importance of information on various topics or questions related to cancer, its treatment or outcomes, and those addressing the sufficiency of information provided on these topics. Studies were included if they provided either a score for the importance/sufficiency of information for each topic or question, ranked topics relative to each other, or reported the overall proportion of patients satisfied with the information provided; descriptive studies that did not provide some form of scoring or ranking were excluded. For some studies, the methodology did not clarify whether the paper addressed overall importance or rather the sufficiency of information, speaking only of 'needs'; these studies were excluded. Studies addressing the importance of information related only to a specific symptom or topic, e.g. genetic counselling or supportive care, were also excluded. As we intended to focus on older patients with a new cancer diagnosis, studies were excluded if the mean or median age of the study population was less than 60 years or if they consisted primarily of patients who had already completed their treatment. Conference abstracts were also excluded.

References of included publications were cross-referenced to retrieve any additional relevant citations.

#### *Data extraction*

For each eligible study, the following data were independently extracted by two investigators (MH, IvW): country in which the study was conducted, study population (age, cancer type, treatment type), and the score or ranking regarding importance or sufficiency of information on each topic or question included in the study.

#### *Quality assessment*

The methodological quality of each of the studies was independently assessed by two reviewers (MH, IvW), using the Newcastle-Ottawa Scale adapted to this subject (Appendix 1a).<sup>7</sup> Disagreement among

the reviewers was discussed during a consensus meeting and in case of persisting disagreement, the assistance of a third reviewer (SR) was sought.

### *Data synthesis and analysis*

Based on the various questionnaires used in the included studies, two reviewers (MH, IvW) discussed and ultimately reached consensus on ten information categories (Table 1): information on cancer itself, prognosis, decision making, treatment options, practicalities, side-effects, self-care at home, functioning and quality of life, dealing with after-effects, and impact on family.

Using this classification, each question or topic used in the included studies was classified into these information categories; if a question or topic was formulated in such a way that it would fit into two categories, it was classified in both. Disagreement among the investigators was discussed during a consensus meeting and in case of persisting disagreement, the assistance of a third reviewer (SR) was sought.

Scores (in points or ranking) provided for the importance or sufficiency of information for each question were allotted to the category the question was classified in, and median score per category per study was subsequently calculated. Next, we made a ranking for each study to determine the relative importance or sufficiency of information per category. The most important category was given 10 points, the second most important 9 points, and so on. For a study addressing all ten categories, ranking would thus range from 10 for the highest ranked category to 1 for the lowest ranked item. If a study addressed less than ten categories, categories would still be ranked consecutively, starting at 10. Thus, a study addressing six categories would be ranked from 10 for the highest to 5 for the lowest ranked item. Next, we determined the overall score of importance or sufficiency per information category by calculating the median ranking in all studies combined.

## **Results**

### *Search and study selection*

The search yielded 4137 studies (1985 from Medline, 2152 from Embase), of which 1541 were duplicates and 2569 were excluded for other reasons. Of these, 27 studies were included in this systematic review: eighteen studies addressing the importance of information topics and thirteen addressing the sufficiency of information provided (four addressing both).

Study details can be found in Table 2.<sup>2,3;5;8-31</sup> Studies included between 15 and 1490 patients, and the median age of the study populations ranged from 60 to 73 years. The studies covered a range

of cancer types, of which prostate cancer was the most commonly assessed (8 studies, 29%); the majority of studies did not focus on a specific treatment type (n=16, 61%).

### *Quality assessment*

Figure 2 provides an overview of the quality assessment; details per study can be found in Appendix 1b. Few studies exclusively addressed older patients, but overall, the representativeness of the study cohorts was not considered to present a risk of bias. The methodology used for the assessment of information priorities and satisfaction with information was clearly described in all studies and the analyses were generally well described. The majority of studies had patients score each item on a range from not important to extremely important/essential and provided the score for each. Fourteen studies provided the score/ranking for each item in the questionnaire while four only provided a ranking of the items relative to each other (Table 3).<sup>3;9;14;30</sup> However, five studies only reported the highest scoring items (ranging from 20-56% of items)<sup>2;3;8;22;31</sup> and four studies only reported the percentage of patients not fully satisfied with information provision without further detail.<sup>16-18;24</sup>

### *The importance of specific information topics*

Eighteen studies addressed the importance of various information topics (Table 3).<sup>2;3;8-15;19;21;22;26-28;30;31</sup> The studies differed significantly in the number of items in the questionnaire, ranging from 7 to 95 items; these items covered a median of eight of the ten information categories (range 5-10). Information about cancer itself and treatment options were included in all eighteen studies, followed closely by information on side-effects, which was addressed in seventeen studies. Information on dealing with after-effects was only included in seven studies.

Patients ranked information about prognosis and the chance of cure as the most important category (median ranking 10, interquartile range (IQR) 8-10), followed by information about cancer itself (median ranking 9, IQR 5.5-9), and about treatment options (median ranking 8, IQR 8-9, Table 3). Information on side-effects of treatment (median 7, IQR 6-8) and on practicalities (median 6, IQR 5-7.5) was also considered important. Least important categories were information about the impact on functioning and quality of life (median ranking 4, IQR 4-7), impact on family (median 4, IQR 2-5.8), and dealing with after-effects (median 4, IQR 3.5-5.5).

### *Sufficiency of information*

Of the thirteen studies addressing the sufficiency of information, seven reported on the proportion of patients that was not satisfied with the information provided or who had wanted more information,<sup>16-18;20;23-25</sup> and nine reported in detail on the information topics for which more information was needed (three reported both).<sup>5;8;11;12;20;21;23;25;29</sup> Overall, one-third of patients felt that they had received insufficient information (range 12-82%).<sup>16-18;20;23-25</sup>

Table 4 shows the details of the nine studies providing a score or ranking on the sufficiency of information on specific topics or questions. Patients rated information about the practicalities of treatment as the most insufficient (median ranking 9.5, Table 4), followed by self-care at home (median ranking 9), and information about prognosis and side-effects (median ranking 8 for both). The three categories least mentioned were information on cancer itself, dealing with the after-effects, and impact on family.

Figure 3 shows the combined results for importance and sufficiency of information.

## **Discussion**

This is a systematic review of 27 studies assessing the information needs of older patients newly diagnosed with cancer. Information about cancer itself and about treatment options were both considered very important and overall, the information provided on these topics was considered satisfactory. Information provision for prognosis and the likelihood of cure, and for side-effects of treatment was generally reported as insufficient, despite both being considered highly important. Although information on the practicalities of treatment and caring for oneself at home during the treatment trajectory was considered only moderately important in comparison to other categories, this was the information that patients felt was lacking the most.

This study has some limitations. First, the classification of information categories was not predefined but developed based on the various questionnaires used in the included studies, through discussion and ultimately consensus between two reviewers (MH, lvW). Other ways of categorization would have been possible and may have yielded somewhat different results, although we do not expect that this would significantly alter the priority outcomes of this review. Second, although we aimed to focus specifically on older patients, very few studies exclusively addressed this population. Third, to allow for combining results from studies using a range of study methods and ways of reporting, we used the median ranking of questions in each of the ten information categories. Points for priority ranking were allotted from 10 down to 1. However, not all studies included all categories; as a result, in a study using all categories the highest priority would score 10 points and the lowest 1, while in a study addressing on six categories the lowest



priority would score 5 points. We tried several methods of remedying this issue, for example by allotting points in steps of 10 divided by the number of categories. However, this would only be a fair representation of the results if the decrease in priority of each information category for patients was similar for each step down, which was not justified based on the study results. In the end, we were unable to fully resolve this issue, which explains why even the lowest ranking categories in Table 3 still have a median ranking of 4 out of 10. Finally, for five studies, we were only able to extract the highest scoring items rather than the full scope of items with associated scores. This could have potentially introduced some bias in outcomes, as having the complete overview over items with associated scores may have resulted in a somewhat different ranking. Despite these limitations, this systematic review provides interesting insight in the information priorities and needs for patients across a range of cancer types. As can be seen in Table 3, there were significant differences in how certain information topics were ranked across studies, demonstrating that there is no one-size-fits-all when it comes to information provision. Within studies, similar patterns were seen; for example, while a significant number of patients rated a question as 'highly important', a similar proportion of patients rated the same question as 'not important at all'.<sup>11</sup> Another study demonstrated that the between-patient agreement on the importance of presented information was only modest at best.<sup>32</sup> Furthermore, that study demonstrated poor agreement between patients and health care professionals. Thus, information has to be tailored to the patient's individual needs, which will require an ongoing dialogue between health care providers and the patient to identify which information categories have the highest priority at any given time.<sup>32</sup>

Overall, one-third of patients in our systematic review reported not receiving sufficient information. This can be improved by empowering the patient to ask questions. Previous studies have shown that question prompt lists in preparation for a consultation with a health care provider increases the likelihood and frequency of question asking, particularly about prognosis.<sup>33-35</sup> This effect seems to be more pronounced when patients are given time to consider the question lists and share it with their family beforehand, rather than for example, receiving the list in the waiting room shortly before the consultation.<sup>33</sup> This also led to fewer unmet information needs,<sup>34</sup> less anxiety,<sup>35</sup> and improved recall.<sup>35;36</sup> Another option is to offer patients two shorter consultations rather than one longer meeting with their health care provider.<sup>37</sup> Having two shorter consultations helps patients process and recall the information that was provided, avoid information overload, more actively search for additional information to increase their understanding, and to involve their support persons to ask the questions most important to them.<sup>37</sup> An additional relevant factor to address unmet information needs is to allow for enough time: patients often feel like there is insufficient

time during the consultation to ask questions,<sup>29</sup> or that they need to make a decision right away, even though most would prefer more time to consider their options.<sup>38</sup> The latter may be addressed by choosing to have two shorter conversations. The first issue is less easily resolved in a busy clinical practice but one option is to actively involve the nursing staff and share the responsibility of information provision across the multidisciplinary team.

Prior studies have shown that when older patients are asked to specifically prioritize various outcomes of oncologic treatment, they are willing to accept a poorer oncologic outcome or shorter remaining life-expectancy if this would increase the likelihood of maintaining independence or quality of life.<sup>39-41</sup> Similarly, decisional regret after oncologic treatment is often associated with a permanent decline in functioning and long-term debilitating sequelae of treatment.<sup>42</sup> In addition, patients report that the presence or absence of a side-effect is less relevant to them than the impact the side-effect has on their physical or social functioning.<sup>43;44</sup> When asked to prioritize research topics for the scientific agenda, patients with cancer rated the impact of cancer on life and how to cope with the after-effects as by far the most important subject for future research. Against this background, information on the impact the cancer or its treatment will have on functioning and quality of life should be considered very relevant to oncologic decision making.<sup>45</sup> Nonetheless, information on the impact of cancer or its treatment on daily functioning, ability to carry out usual activities, and quality of life was given very low priority by patients themselves (Figure 3).

This highlights an interesting dilemma for health care professionals providing information to patients newly diagnosed with cancer. The amount of information patients are confronted with in the weeks after diagnosis can be overwhelming. Patients' needs seem to focus on understanding their situation, treatment options, as well as very practical questions (i.e. 'how do I prepare myself for treatment?', 'will my insurance cover the costs of this treatment?', 'do I take the medication with food?', and 'who can I call if I have questions?').<sup>8;21</sup> The focus is thus on questions about the short term future and all the uncertainties that come with it. Taking a step back and thinking about how choices that are being made at present will affect future functioning and quality of life may (in some ways) be too much to ask. At the same time, if we want to improve long-term, patient-centred outcomes of oncologic treatment and decrease decisional regret, this is exactly what we must encourage our patients to take seriously into consideration during the decision-making process. It may be worthwhile to develop question prompt lists with explicit inclusion of potential longer term outcomes, asking patients to take some time prior to the consultation to consider what outcomes matter most to them.

*In conclusion*, this systematic review demonstrates that currently, patients report that information about the cancer itself and about treatment options is sufficiently addressed, while information

about prognosis, practicalities of treatment and self-care at home could be improved. However, there is significant heterogeneity among patients regarding which information is most important to them, thus requiring an ongoing dialogue between patients and health care providers about which information is most needed at any given time. This process could be supplemented with question prompt lists, provided well in advance of the consultation, and with incorporating sufficient time for the patient to ask questions and process the information during and after the initial consultation.

#### *Conflict of interest*

The authors have no conflict of interest to declare

#### *Author contribution*

Conception and design: Marije Hamaker, Siri Rostoft

Data collection: Marije Hamaker, Inez van Walree

Analysis and interpretation of data: all

Manuscript writing: Marije Hamaker, Inez van Walree

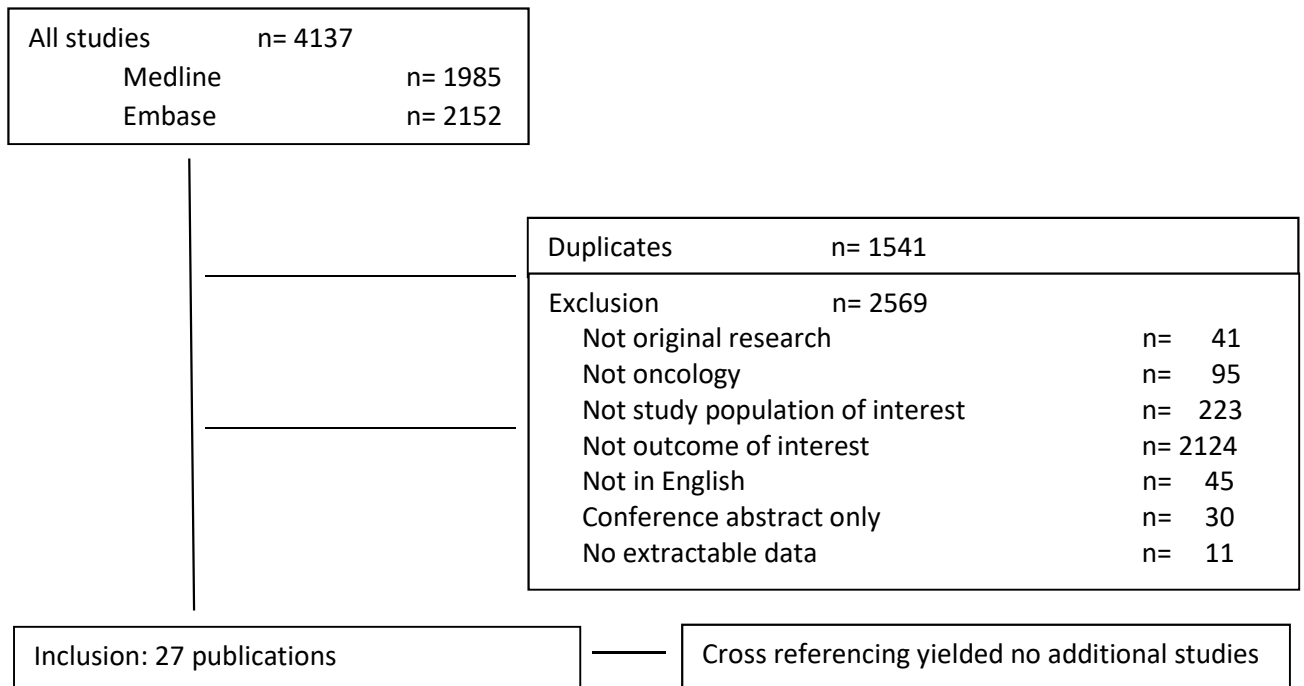
Approval of final article: all

All authors read and approved the final manuscript.

**Table 1. Classification of information topics**

<b><i>Topic</i></b>	<b><i>Definition</i></b>
Cancer itself	Information about cancer, its diagnosis, stage, symptoms, and natural course
Prognosis	Information about prognosis, risk of recurrence, and the likelihood of cure from the disease, including how cure can be determined
Decision making	Practical information about the decision-making process, sources of information, and other decision support options
Treatment options	Information about the goals of treatment, what oncologic treatment options are available, now and in future, how they work, and what the benefit could be
Practicalities	Information about the practicalities of testing, treatment, follow-up and monitoring, and the composition and qualifications of the treatment team
Side-effects	Information on side-effects of treatment, including when and what to report, and risk of serious adverse events
Self-care at home	Information about caring for oneself at home, self-management of side effects, preventing further risks, complementary medicine
Functioning and quality of life	Information on the impact on (long term) functioning, one's ability to carry out usual activities, and quality of life
Dealing with after-effects	Information about treatment options for persisting negative (treatment) effects, including possibilities for coping support
Impact on family	Information about the impact of the disease on the family and significant others, including risk of developing cancer themselves

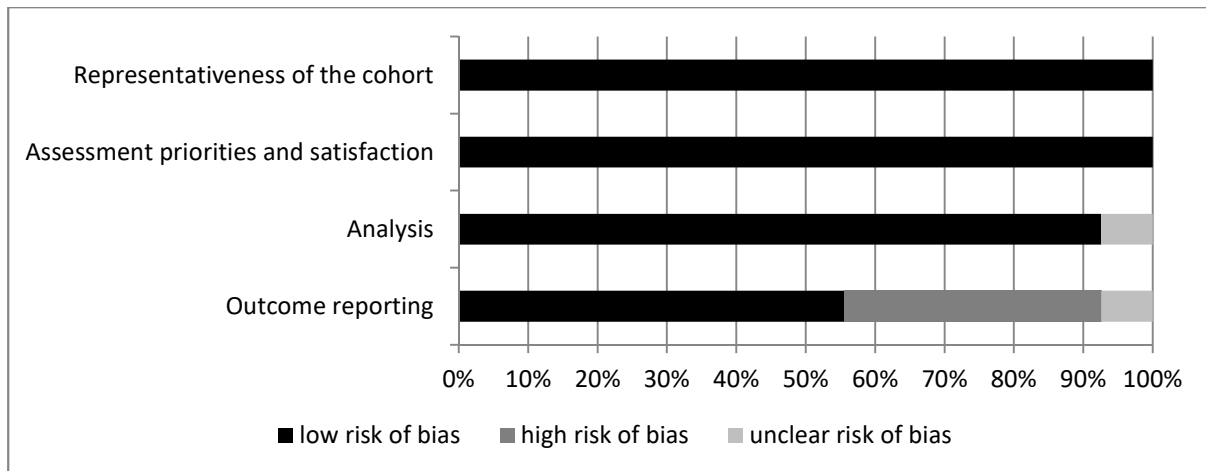
**Figure 1. Search results and study selection**



**Table 2. Included studies**

Author	Publication year	Country	Cancer type	Specific treatment type?	n=	Me(dj)an age in years*	Importance of information	Sufficiency of information
Andreassen <sup>8</sup>	2007	Sweden	Oesophageal	No	15	69 (58-86)	X	X
Browall <sup>9</sup>	2004	Sweden	Ovarian	No	64	62 (25-81)	X	
Carney <sup>10</sup>	2006	UK	Colorectal	No	22	72 (40-86)	X	
Dale <sup>11</sup>	2004	UK	Prostate	No	96	73 (57-93)	X	X
Ellis <sup>12</sup>	2018	USA	Various	No	176	62.9 ± 12.3	X	X
Feldman-Stewart <sup>13</sup>	2000	Canada	Prostate	No	38	64.6 ± ?	X	
Feldman-Stewart <sup>14</sup>	2001	Canada	Prostate	No	71	65.7 ± 6.6	X	
Feldman-Stewart <sup>3</sup>	2010	International	Prostate	No	659	~ 67	X	
Feldman-Stewart <sup>15</sup>	2013	Canada	Breast	Endocrine	188	67 ± ?	X	
Gillespie <sup>2</sup>	2017	Canada	HPB	Surgery	36	? (>65)	X	
Iconomou <sup>16</sup>	2002	Greece	Various	Chemotherapy	100	59.7 ± 12.1		X
Llewellyn <sup>17</sup>	2006	UK	HN	No	82	59.9 ± 12.5		X
Mancini <sup>18</sup>	2015	France and Australia	Haematological	No	301	71 (19-93)		X
McNair <sup>19</sup>	2013	UK	Upper GI	Surgery	136	66 ± 8.8	X	
Newell <sup>20</sup>	2004	UK	HN	Surgery	29	~64		X
O'Connor <sup>21</sup>	2010	UK	Rectal	No	40	~ 67	X	X
Papadakos <sup>22</sup>	2018	Canada	HN	No	450	61 (18-94)	X	
Rood <sup>23</sup>	2015	Netherlands	Haematological	No	458	60.2 ± 13.7		X
Ross <sup>24</sup>	2013	Denmark	Various	No	1490	? (>60)		X
Scheer <sup>5</sup>	2012	Canada	Rectal	Surgery	30	65 (42-89)		X
Templeton <sup>25</sup>	2003	UK	Prostate	Endocrine	90	~73		X
Thavarajah <sup>26</sup>	2015	Canada	Prostate	Radiotherapy	31	? (>60)	X	
Van Weert <sup>27</sup>	2013	Netherlands	Various	Chemotherapy	116	71.9 ± 4.4	X	
Wang <sup>28</sup>	2017	USA	Breast	Radiotherapy	93	72.5 (65-93)	X	
Watson <sup>29</sup>	2019	Australia	Haematological	No	170	~ 60		X
Wolpin <sup>30</sup>	2016	USA	Prostate	Radiotherapy	35	65.7 ± 11.0	X	
Wong <sup>31</sup>	2000	Canada	Prostate	No	101	70 ± 7	X	

**Figure 2. Quality assessment**



**Table 3. Information priorities for patients newly diagnosed with cancer.** Numbers represent median ranking within studies. The most important information category was given 10 points, the second most important 9 points, and so on down to the lowest ranking, which is 1 in case all ten categories were addressed but would be higher in case of fewer included categories. \* na = not applicable

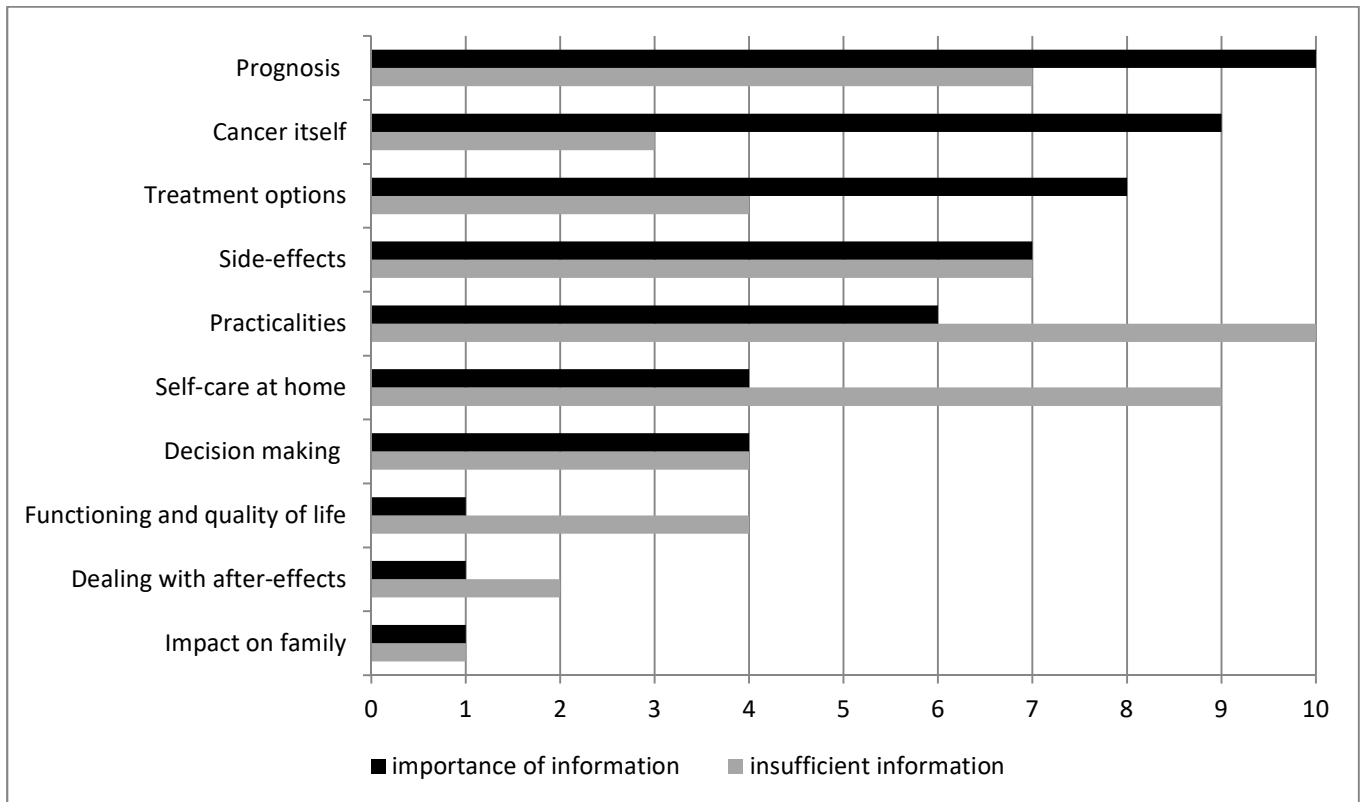
STUDY		SURVEY METHODOLOGY					INFORMATION PRIORITIZATION RANKING									
Author	Year	No. of questions in questionnaire	No. of categories addressed	No. of answer options	Reporting	No. of questions with outcome reported	Prognosis	Cancer itself	Treatment options	Side-effects	Practicalities	Self-care at home	Decision making	Functioning and quality of life	Dealing with after - effects	Impact on family
Andreassen <sup>8</sup>	2006	64	6	3	Score	13 ( 20%)	-	4	8	6	7	5	-	-	9	10
Browall <sup>9</sup>	2004	9	8	na*	Ranking	9 (100%)	10	9	8	7	-	6	-	4	3	5
Carney <sup>10</sup>	2006	13	7	4	Score	13 (100%)	10	5	9	8	7	5	5	-	-	6
Dale <sup>11</sup>	2004	20	8	4	Score	20 (100%)	-	7	9	-	10	5	6	4	-	8
Ellis <sup>12</sup>	2018	7	5	4	Score	7 (100%)	8	10	7	9	6	-	-	-	-	-
Feldman-Stewart <sup>14</sup>	2001	59	10	3	Ranking	59 (100%)	8	9	10	7	6	5	3	4	-	2
Feldman-Stewart <sup>13</sup>	2000	93	10	4	Score	93 (100%)	6	8	10	4	9	2	4	8	5	1
Feldman-Stewart <sup>15</sup>	2013	95	10	4	Score	95 (100%)	10	9	8	5	6	4	7	3	-	-
Feldman-Stewart <sup>3</sup>	2010	92	7	4	Ranking	20 ( 22%)	10	8	9	7	5	-	6	-	-	-
Gillespie <sup>2</sup>	2017	45	10	5	Score	25 ( 56%)	5	9	10	8	-	7	-	6	-	-
McNair <sup>19</sup>	2013	52	11	5	Score	52 (100%)	10	4	9	8	5	6	1	7	3	2
O'Connor <sup>21</sup>	2010	53	11	5	Score	53 (100%)	10	2	5	7	6	9	1	8	4	3
Papadako <sup>22</sup>	2018	59	6	3	Score	12 ( 20%)	10	9	8	6	2	7	-	3	4	5
Thavarajah <sup>26</sup>	2015	74	10	4	Score	74 (100%)	10	10	8	6	4	5	3	7	-	-
Van Weert <sup>27</sup>	2013	67	11	4	Score	67 (100%)	3	10	7	8	5	4	9	2	6	1
Wang <sup>28</sup>	2017	24	9	4	Score	24 (100%)	10	5	7	9	9	6	-	-	-	-
Wolpin <sup>30</sup>	2016	9	8	na*	Ranking	9 (100%)	10	9	8	6	7	3	5	4	-	-
Wong <sup>31</sup>	2000	43	7	5	Score	11 ( 26%)	-	10	10	5	10	6	7	4	-	-
<b>MEDIAN RANKING</b>							10	9	8	7	6	5	5	4	4	4
Number of studies addressing this information category							15	18	18	17	16	16	12	13	7	10



**Table 4. Ranking of topics according to sufficiency of information.** Numbers represent median ranking within studies. The category with the poorest reported sufficiency, and thus the highest ranked information need, was given 10 points, the second most important need 9 points, and so on down to the lowest ranking, which is 1 in case all ten categories were addressed but would be higher in case of fewer included categories.

Author	Year	Practicalities	Self-care at home	Prognosis	Side-effects	Decision making	Treatment options	Functioning and quality of life	Cancer itself	Dealing with after-effects	Impact on family
Andreassen <sup>8</sup>	2006	9	6	-	-	7	10	-	8	5	-
Dale <sup>11</sup>	2004	10	8	-	3	9	6	4	7	-	5
Ellis <sup>12</sup>	2018	10	-	9	8	7	-	-	6	-	-
Newell <sup>20</sup>	2004	10	9	-	2	8	5	7	6	3	4
O'Connor <sup>21</sup>	2010	10	9	-	8	7	6	-	5	-	-
Rood <sup>23</sup>	2015	-	-	8	10	-	7	10	-	-	-
Scheer <sup>5</sup>	2012	7	9	5	10	-	8	5	6	5	-
Templeton <sup>25</sup>	2003	7	9	-	8	-	7	-	-	10	-
Watson <sup>29</sup>	2019	9	-	-	8	-	-	10	-	7	-
<b>MEDIAN RANKING</b>		9,5	9	8	8	7	7	7	6	5	4,5

**Figure 3. Importance and sufficiency of information per category on a scale of one to ten.** Longer lines represent greater importance (in black) or greater insufficiency (in grey)



**Appendix 1a. Quality assessment criteria based on the Newcastle-Ottawa Scale<sup>7</sup>**

1. Representativeness of the exposed cohort	<ul style="list-style-type: none"> <li>+ representative of the average older cancer patient</li> <li>± cohort includes patients younger than 60 years or median age below 70</li> <li>- selected group of patients</li> <li>? no description of the derivation of the cohort</li> </ul>
2. Assessment of patient priorities and satisfaction	<ul style="list-style-type: none"> <li>+ clear description of definition and method of assessment</li> <li>? unclear description of definition and method of assessment</li> <li>? no description</li> </ul>
3. Analysis	<ul style="list-style-type: none"> <li>+ clear description of method of analysis</li> <li>? unclear description of method of analysis</li> <li>? no description</li> </ul>
4. Outcome reporting	<ul style="list-style-type: none"> <li>+ scores for all outcome items reported</li> <li>± ranking for all outcome items reported</li> <li>- scores or ranking only reported for a limited number of outcome items</li> <li>- only % of patients reported that wanted more information or was not satisfied with received information</li> <li>? unclear whether all outcomes were reported</li> </ul>

**Appendix 1b. Quality assessment per study**

<b>Author</b>	<b>Year</b>	<b>Representativeness of the cohort</b>	<b>Assessment priorities and satisfaction</b>	<b>Analysis</b>	<b>Outcome reporting</b>
Andreassen <sup>8</sup>	2007	±	+	+	-
Browall <sup>9</sup>	2004	±	+	+	±
Carney <sup>10</sup>	2006	±	+	+	+
Dale <sup>11</sup>	2004	±	+	+	+
Ellis <sup>12</sup>	2018	±	+	+	+
Feldman-Stewart <sup>13</sup>	2000	±	+	+	+
Feldman-Stewart <sup>14</sup>	2001	±	+	+	±
Feldman-Stewart <sup>3</sup>	2010	±	+	+	-
Feldman-Stewart <sup>15</sup>	2013	±	+	+	+
Gillespie <sup>2</sup>	2017	±	+	+	-
Iconomou <sup>16</sup>	2002	±	+	+	-
Llewellyn <sup>17</sup>	2006	±	+	+	-
Mancini <sup>18</sup>	2015	±	+	+	-
McNair <sup>19</sup>	2013	±	+	+	+
Newell <sup>20</sup>	2004	±	+	?	?
O'Connor <sup>21</sup>	2010	±	+	+	+
Papadakos <sup>22</sup>	2018	±	+	+	-
Rood <sup>23</sup>	2015	±	+	+	+
Ross <sup>24</sup>	2013	±	+	+	-
Scheer <sup>5</sup>	2012	±	+	?	?
Templeton <sup>25</sup>	2003	±	+	+	-
Thavarajah <sup>26</sup>	2015	±	+	+	+
Van Weert <sup>27</sup>	2013	+	+	+	+
Wang <sup>28</sup>	2017	+	+	+	+
Watson <sup>29</sup>	2019	±	+	+	+
Wolpin <sup>30</sup>	2016	±	+	+	±
Wong <sup>31</sup>	2000	+	+	+	-

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