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REVIEW

Harmful communication behaviors in cancer care: A systematic review of patients and family caregivers perspectives

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Abstract

Objective: Issues regarding clinician communication remain an important source of complaints within healthcare. This systematic review aims to determine cancer patients' and their family caregivers' views on which clinicians' communication behaviors can harm (i.e. eliciting negative feelings/consequences for patients/family caregivers).

Methods: We searched for all types of peer-reviewed studies that determined adult (≥18 years) cancer patients' and/or family caregivers' perspectives on which clinicians' communication behaviors can harm in several databases (PubMed, Embase, Web of Science, Cochrane Library, Emcare, PsycINFO and Academic Search Premier), supplemented by expert-consultation. Studies were screened using the Artificial intelligence screening tool of ASReview and data was analyzed using Thematic Analysis. To assess the quality of the studies the Qualsyst critical appraisal tool was used.

Results: A total of 47 studies were included. Four main themes of harmful communication behaviors were identified: (1) Lack of tailored information provision (e.g. giving too little or too much/specific information) (2) Lack of tailored decision making (ranging from; patient exclusion, to the patients' responsibility, and/or haste) (3) Lack of feeling seen and heard (seen as a disease, not as a human being; not listened to concerns and emotions) (4) Lack of feeling held and remembered (forgotten agreements; lack of care continuity).

Conclusions: Our results reveal an overview of patients' and family caregivers' perspectives on which clinicians' communication behaviors can harm. Harm could be prevented when information and decision involvement are tailored and patients' and family caregivers' needs to feel *seen*, *heard*, *held* and *remembered* are met.

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KEYWORDS
cancer, communication, complaints, family caregiver perspective, harm, oncology, patient perspective, systematic review

1 | BACKGROUND

What starts by hearing the words "*You have cancer*.." may be followed by difficult decisions, intensive treatments, side effects, anxiety and an uncertain future. Both for patients and their family caregivers (i.e. patients' loved ones including, but not limited to, relatives), the impact of cancer is enormous.[1–3] During the disease process patients and family caregivers experience a need for appropriate information (e.g. to make shared and well-informed decisions) and a need for support and empathy, in order to cope with their changing life perspectives.[4,5] Clinicians play a major role in meeting these needs.[6]

Helpful communication behaviors (e.g. responding to emotions, reassuring, providing tailored information) has been shown to consistently improve feelings of trust, satisfaction, recall of information and can decreases anxiety.[7–12] These helpful communication behaviors are increasingly incorporated into medical education.[13–17] Nevertheless, what is perceived as harmful communication is less clear, even though dissatisfaction with communication remains an important topic in patient-driven second opinions[18] and many complaints within the medical system are about communication.[19,20] It has also been shown that harmful communication might increase unnecessary psychosocial distress.[21] We define harmful communication behavior as clinicians' communication behavior which has the potential to unnecessarily harm (i.e. elicit negative feelings/consequences) patients or their family members. Recently, in a first-of-its-kind study, our research team explored the patient perspective of clinicians' harmful communication[22] and found, in line with other studies,[23–27] that patients' communication preferences–for example, about the preferred amount of information–often vary. This implies that there may be potential harm in not meeting their preferences.[22]

Importantly, while it is known that patients' family caregivers experience high levels of distress during the patients' disease trajectory,[3,28] which communication behaviors they specifically perceive as harmful is also largely unknown. What we do know is that approximately 40% of family caregivers' needs are not met, due to lacking clinicians' communication behavior.[29] For example, family caregivers perceive deficits in receiving understandable information and being informed about who could help them with problems.[29]

We sought to better understand what patients and family caregivers specifically perceive as harmful communication behavior. The aim of this systematic review is therefore to determine cancer patients' and family caregivers' views on which clinicians' communication behaviors can harm. This may provide an important stepping stone to help clinicians improve their communication and further impact patient-reported outcomes by meeting communication needs.

2 | METHODS

The systematic review protocol was published in the PROSPERO register (registration number: CRD42021236083) and adhered to the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses).[30]

2.1 | Database search

In cooperation with an experienced librarian (JS), a detailed search strategy was composed (see Appendix S1). The following databases were searched: PubMed, Embase (OVID-version), Web of Science, Cochrane Library, Emcare (OVID), PsycINFO (EBSCOhost) and Academic Search Premier. The query consisted of the combination of the following four concepts: (I) Cancer (II) Harmful communication (III) Patients (IV) Family caregivers. For these concepts, all relevant keyword variations were used. The search strategy was optimized for all consulted databases, taking into account the differences of the various controlled vocabularies as well as the differences of database-specific technical variations. The search was limited to the adult population and was performed on 20 June 2022. In addition to the database search, we e-mail consulted international experts (16 experts were approached, 13 responded, see Acknowledgments) in the field of clinician-patient communication for potentially relevant articles.

2.2 | Eligibility

Studies were included if they met the following criteria: peer-reviewed article including data (e.g. qualitative studies, case reports, observational studies, RCT and systematic reviews), full text available, participants were adult (≥18 years) cancer patients (or survivors) AND/OR family caregivers, focus on cancer, reporting about harmful communication (i.e. eliciting negative feelings/consequences) by clinicians from a patients' or family caregivers' perspective.

2.3 | Study screening

Title/abstract and full text screening were supported by a Microsoft Excel form to note the reasons for in- or exclusion. Following a pilot test of the Microsoft Excel form, 20% of the studies were double screened on title and abstract by JW/TW (absolute agreement was 90%). Disagreements were discussed with LV, until consensus was reached. Next, the Artificial Intelligence (AI) screening tool ASReview

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was used by JW for screening the rest of the studies on title and abstract.[31] Recently published systematic reviews described this tool as helpful in their screening process.[32–34] ASReview is a free and open-access machine learning technology used to save time and prevent from bias[35] and human errors.[36] To optimize the reliability of using ASReview we well prepared the AI screening process by means of the 20% double screening. The double screened included studies were manually added to ASReview in order to train the AI tool. ASReview then uses active learning to influence the order of articles based on relevance for the inclusion process. Sorting ensures that when many articles are excluded in a row, it can be assumed that the articles after can be labeled as irrelevant.[37,38] ASReview developers advised a screen-stop decision after 100–120 consecutively excluded studies. However, to ensure we would not miss any studies we decided on a screen-stop decision after 150 consecutively excluded studies.[39] JW/TW independently screened the remaining studies on full text and disagreements were solved by discussion (if needed with LV). Studies from the experts input were manually double-screened by JW/TW. LV double checked all the included studies of JW/TW on eligibility.

2.4 | Data extraction and analysis

Several characteristics of the articles were extracted: first author, year of publication, country, sample size, participant characteristics (e.g. patient/family caregiver, age, type of cancer), type of clinician, study aim/design and type of harmful communication behavior. Initially, we aimed to perform a systematic review including a meta-analysis. However, due to the limited availability of quantitative data, a meta-analysis was not feasible. Consequently, we incorporated the quantitative data as harmful communication topics in the qualitative analysis. Thematic analysis was subsequently used to analyze the data concerning the harmful communication.[40] First, JW/TW independently read through the articles and identified the important reflections from participants on harmful communication. All quotations about harmful communication were highlighted in the articles and then copied to ATLAS.ti software. In step two, JW gave initial codes to all quotations (e.g. use of jargon, lack of support). Third, JW/TW/LV together discussed how to collate the codes into potential themes/groups (e.g. information provision, decision making). Then JW collated all codes under higher order themes and again discussed this with LV. Fourth, the themes were summarized and reviewed with all co-authors. Last, the co-authors' feedback was processed and final themes were defined.

2.5 | Study quality

To assess the quality of the studies the Qualsyst critical appraisal tool by Kmet et al.[41] was used. Authors JW/TW independently assessed all studies and their agreement was calculated.

3 | RESULTS

3.1 | Literature search

From 3621 database retrieved studies and 43 expert selected studies, in total 47 studies were included in this review (see Flowchart in Figure 1). These studies were published between 2002 and 2022, conducted in 14 countries (mostly USA, $n = 20$) and involving a total of 4123 adult cancer patients and 231 family caregivers. Most patients (66%) were female and most (62%) family caregivers were male (three studies did not report gender). Eleven studies included family caregivers. Most studies focused on mixed types of cancer ($n = 20$). Eighteen studies included patients with advanced cancer. Studies had qualitative designs ($n = 42$) or used mixed methods ($n = 5$; quantitative data were only used as input for qualitative themes). Quality of the included studies was either strong ($n = 44$) or good ($n = 3$)[41] and the agreement between JW/TW was 92%. Detailed study characteristics were provided in Appendix S2.

3.2 | Harmful communication

Four main themes of harmful communication behaviors were identified: (1) Lack of tailored information provision (2) Lack of tailored decision making (3) Lack of feeling seen and heard (4) Lack of feeling held and remembered. (Sub)themes are described below with additional supporting quotations shown in Appendix S3.

3.2.1 | Theme 1: Lack of tailored information provision

Too few and too many provided treatment options, and information about these options, could make it more difficult for patients to make well-considered decisions

Patients reported how both too few[22,42–48] and too many[22,49–53] provided treatment options, and information about these options, could harm because both make it difficult for patients to make well-considered decisions. For example, patients mentioned that sometimes information about complementary and alternative treatment was lacking, while they wanted to include this in their considerations. Discussing too many treatment options could overwhelm patients, especially when someone just received shocking news. In addition, family caregivers mentioned that too much information at once was difficult to process for the patient.[42]

Lack of information about treatment consequences could increase distress and make it more difficult to make well-informed decisions

Patients reported on how too little information on treatment consequences (e.g. side effects, fertility consequences)[25,42,43,45,46,48,50–59] could increase feelings of distress (e.g. anxiety and discouragement). A

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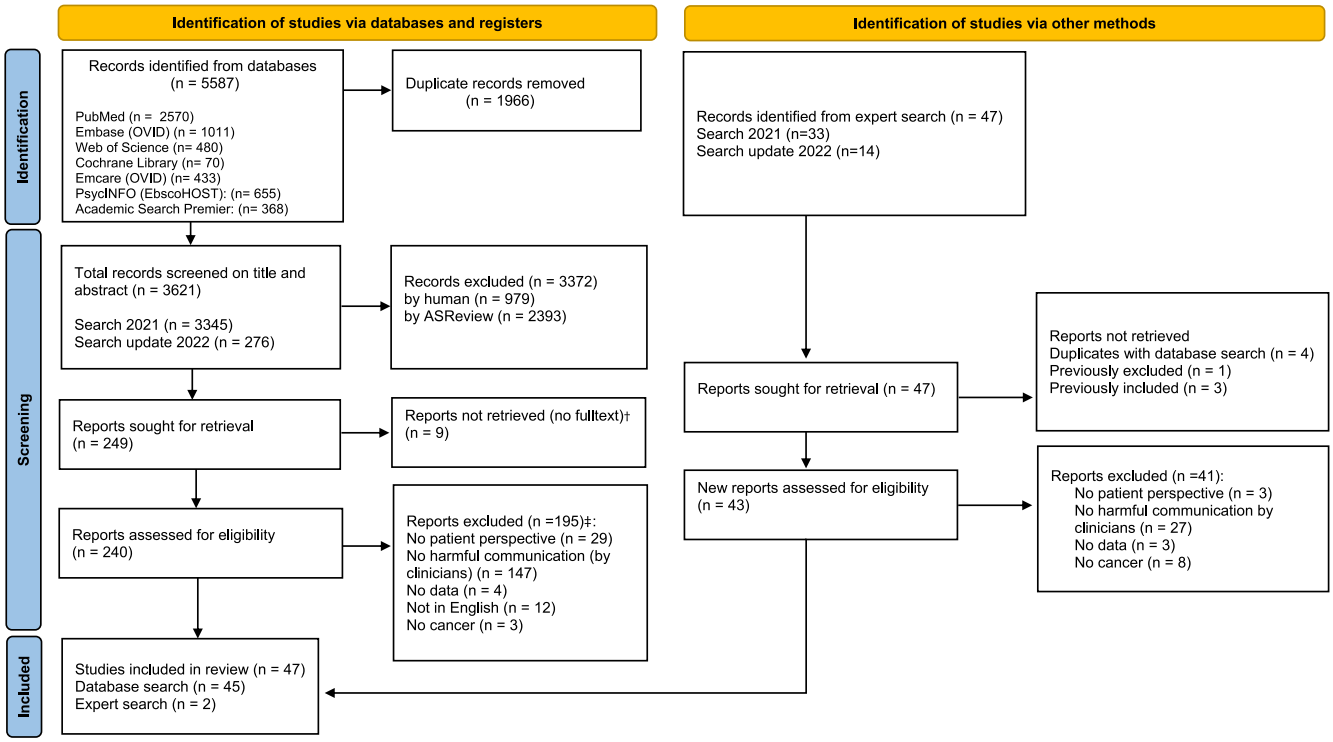

FIGURE 1 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources. †First authors were e-mailed and asked for full text of these studies. When there was no response or possibility to provide full text, studies were excluded. ‡Some studies were excluded due more than one reason. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/.

lack of information made patients feel uninformed about what to expect, which makes it more difficult for them to prepare for what is to come and to make well-informed decisions. When patients have to deal with potential consequences (e.g. side effects or fertility consequences) they were not prepared for, it could make patients feel upset and cause loss of confidence.

Too much test result information could overwhelm and too little keeps it uncertain

Patients reported that providing either too much and too little information about tests could be harmful.[22] Too much detailed information may be incomprehensible to patients and overwhelm them. Too little information (e.g. only mentioning it is good or bad) leaves the situation for patients unclear.

Prognostic information provision could be harmful when timing is poor and patients receive numeric or vague information

With regard to timing of prognostic information, patients especially perceived harm when prognostic information was discussed too early.[25,44,45,55,60–65] This could cause anxiety and take away hope, which some patients so desperately need to stay upright mentally and physically. In contrast, caregivers reported that it is harmful when prognostic information is discussed too late (too close to death)[66,67] as it takes away the time to say goodbye to a loved one. Starting too late[61,66,67] with discussing the approaching end of life (too close to death) could also cause false hope (for both patient and caregiver). For some, receiving numerical prognostic information was perceived as harmful[22,25,62,63,65,68] because this number is inherently uncertain, but it can get stuck in patients' minds, causing them to suffer mentally (e.g. increase anxiety). For others, vague or partial information about prognosis could be harmful[22,51,62,67] because it makes it unclear for patients and caregivers where they stand.

Contradictions in information (e.g. from different clinicians) may cause confusion and feelings of helplessness

Inconsistent information (different clinicians providing different information) made patients[25,42,46,50,51,53,55,56,60,63,69–71] and their family caregivers[60,66] confused, frustrated and could increase feelings of helplessness. As a result of conflicting information, family caregivers experience difficulties in understanding the situation of their loved one.

Jargon could diminish understanding and lead to anxiety

Clinicians using confusing language (e.g. medical jargon) that prevents patients[22,42,48,51,55,57,60,61] and their family caregivers[60,66] from fully comprehending the provided information which could increase confusion, uncertainty and fear.

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3.2.2 | Theme 2: Lack of tailored decision making

Exclusion from treatment decisions is impersonal and could cause distress

Excluding patients from the decision making process has been identified as potentially harmful[22,25,51,57,59,72–74] as it could increase patients' distress and make them feel like they do not participate in the conversation. Occasionally patients mentioned clinicians forcing treatments upon them, making them feel as if they are a medical case and not a person.

Making treatment choices entirely the patient's responsibility could be overwhelming and stressful

Leaving the treatment decision completely to the patient (lack of an advice)[50,51,58,62,70] may be undesirable because some patients get overwhelmed by this responsibility and believe that they don't have enough knowledge to make such a difficult and important decision.

Forcing patients to hasty decisions result in ill-considered choices due to lack of room for the options to sink in

Patients being forced by their clinician to make a hasty decision was perceived as harmful communication behavior[49,51,58,62] because then there was no room for the information and situation to sink in.

3.2.3 | Theme 3: Lack of feeling seen and heard

Providing information in an inappropriate manner; rude, cold and uncaring

The manner in which information is provided to patients matters too. Patients[22,25,42,44,45,48–50,56,57,59–63,72,75] and family caregivers[25,42,60,66–68,72] described harmful manners of communication (causing dissatisfaction and anger): rude, uncaring, impolite, unpleasant, inhumanely, insensitively, thrown in the face, cold and uncivil.

Inadequately addressing concerns seriously left patients feeling dismissed and could lower feelings of confidence and trust

A lack of taking patients' concerns seriously (e.g. ignoring or not taking patients' physical complaints serious) is perceived as harmful by patients[22,42,44,45,49,50,71,76–78] because it left them feeling dismissed. This could lower their trust in the clinician. This theme was most frequently described by patients who were not taken seriously in early stages (prior to diagnosis). As a result, physical complaints and feelings of desperation may increase.

A lack of validation of, or not responding to, patients' concerns and emotions could increase anxiety and feelings of loneliness

A lack of validation of the patients' situation and their (emotional) concerns was perceived as harmful (e.g. failure to respond to patients' emotional cues).[22,25,46,50,51,54,56,57,61–63,71,73,77–84] When patients' concerns are not taken seriously (e.g. about side effects), it may increase anxiety and feelings of loneliness. Concrete examples of (well-intentioned) comments that could be perceived as harmful because they lack validation of patients' situation are "*You look great*"[22] (gives patients no room to indicate if they don't feel well at all) and "*Luckily you have the 'good' cancer*"[80] (downplayed the diagnosis/gives the feeling patients do not need much support).

Lack of a personal approach could give the impression that clinicians do not care about the patient and family caregiver as a person

Not seeing/treating the patient as a person was perceived as harmful.[22,25,51,56,57,60,62,63,72,78,82,84] A rushed attitude, not using someone's name and no interest in someone's life besides the disease was experienced as disrespectful and patients got the feeling that they are treated as a number, a diagnosis/case or a "*piece of meat.*"[84]

Not taking into account the role and needs of family caregivers could cause feelings of marginalization

Both patients[54,71] and family caregivers themselves[25,42,46,66,67,79,85] mentioned that the role and needs of family caregivers should not be forgotten. When family caregivers were not included in conversations, were not aware of their loved one's situation, and (existential) support for them was lacking, their distress could increase and they feel marginalized.

3.2.4 | Theme 4: Lack of feeling held and remembered

Experiencing a lack of time for concerns to be properly heard could make patients feel like a burden

When clinicians' (non)verbal communication shows that there is no or too little time for patients' concerns to be properly heard,[25,42,46,51,54,55,57,61–63,72,73,77–79,81–83] this could make patients feel like a burden, and therefore they were second guessing themselves with their worries/concerns. More specifically, patients with incurable cancer (and their family caregivers) mentioned that providers who exhibited a lack of time, made them feel dismissed and "written off." Several of these patients interpreted such dismissals as messages they were no longer important because their disease could no longer be cured.

Specific harmful examples were cited by both patients and family caregivers. First, healthcare professionals explicitly mentioning how busy they are.[42] Second, nonverbal behavior such as hurried body language or looking at a watch.[62] Third, unexpectedly receiving information or a diagnosis by letter or telephone (resulting in unanswered questions and lingering concerns).[42,46,81] Fourth, the lack of room to ask questions in general,[25,42,50,54,55,57,72,73,81] caused more persistent stress in patients.

Excessive waiting and not keeping appointments could increase distress

In several studies patients[22,45,46,55,57,66,81,82] and family caregivers[42,46,55,66] reported it as harmful when they had to wait excessively (e.g. for promised appointments or calls). Especially waiting for important information (e.g. test results), after the agreed time is

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exceeded, was perceived as harmful because patients are in suspense/fear which increases with time. Also vague promises (e.g. "*I call you on Friday..*")[22] were perceived as harmful because this leaves patients feeling unsettled and insecure.

Experiencing a lack of continuity of care could increase uncertainty, confusion and feelings of abandonment

Insufficient continuing care and (existential) support for patients' needs increases anxiety, uncertainty, confusion and feelings of loneliness.[22,43,50,54,55,57,59–61,71–73,77–79,86] Specifically stating that "*there is nothing more we can do for you*"[77] was experienced as extremely destroying because it takes away hope and made patients feel abandoned. Lack of continuation of the same care providers was also perceived as harmful to patients[57,60,71,78,86] and caregivers,[60,66] because patients have to tell their story over and over to different clinicians.

4 | DISCUSSION

This systematic review aimed to determine patients' and their family caregivers' views on which clinicians' communication behaviors can harm. A thematic analysis of the literature revealed that harm might occur when these four needs of patients and family caregivers were not met: (1) *need for tailored information provision*, (2) *need for tailored decision making*, (3) *need of feeling seen and heard*, and (4) *need of feeling held and remembered*.

As we found that both untailored information-provision (e.g. too little vs. too much) and untailored decision-making (e.g. excluding patients vs. making them feel responsible) were perceived as harmful, it is interesting to note that patients' reasons for preferring all information versus those who do not want all information and whether they want to be actively involved in decision-making seem to overlap. In line with other studies, patients reported a need for control and autonomy as reasons for preferring much information (e.g. about prognosis) and active participation in decision making.[87,88] Patients who prefer less information and a more paternalistic decision making approach do not feel capable enough to comprehend such important information and decisions.[87,89,90] Of course, this does not automatically mean that people who want much information also prefer to be actively involved in all decision-making, and vice-versa (although older literature does hint toward this[91,92]). This might be most apparent in patients with low health literacy, as patients might not ask many questions,[93] but do benefit from receiving information[94] and want to be involved in decision-making.[95] To do so, in line with our results, strategies such as not using jargon and providing too much information at once are likely essential first steps to prevent harmful communication.[96]

The perceived harmfulness of not feeling *seen*, *heard*, *held and remembered* adds to the large available literature on the importance of clinician-expressed empathy.[97–99] Within the wider construct of clinical empathy[100] both, the need to be seen (as human being) and the need to be heard (concerns should be listened to), overlap with what other researchers have previously described as the need to *feel known*[5] and to *'feeling heard and understood'*.[101] What our study adds is a new dimension of the need to feel *held and remembered* (continuous care). Previous studies show that patients perceive good institutional resources and care processes (e.g. kept agreements, same clinicians) as an important value.[78,102] However, never before was highlighted that these themes show an underlying need to be *held and remembered*.

4.1 | Clinical implications

To prevent harm in information provision and decision making, tailoring is essential. First, the preferred amount of information someone wants can be tailored both in general (e.g. "*Some people prefer very detailed information, others prefer to hear only the rough picture, and then there are those in the middle. What kind of person are you?*"[5]), and in specific topics (e.g. about prognosis: "*Some people, but not all, want information about their life expectancy. It's different for everyone. What are your needs here?*"[22,23]). It's noteworthy to acknowledge potential friction that arises when the patient prefers not to receive detailed information about all treatment options (to avoid becoming overwhelmed) while the clinician is obligated to maintain the principles of complete informed consent. Helpful would be to provide all options without going into exhaustive details of all potential side effects.[103] Second, the preferred extent of involved decision-making can be tailored (e.g. "*Some people want to make decisions together; others want to do it themselves. What are your needs? Would you like to hear my recommendation at this point?*"[22,23]). We should note, however, that patients' preferences are no fixed beliefs, and are prone to change over time (e.g. when patients become sicker).[104,105] Repeatedly exploring patients' preferences can be helpful,[106,107] while future studies can explore (using longitudinal methods) how patients' needs change during the disease process.[108] Moreover, we could speculate that when patients enter the incurable phase of their illness, their information and decision needs shift toward a "*what matters most*" approach,[102,109,110] in which it is not always necessary to discuss all information and options. It might be more important to individually explore what matters most to someone (e.g. "*What are your most important goals?*"[111]), and to prepare for hypothetical deterioration[112] (e.g. "*It can be difficult to predict what will happen. I hope you will feel as well as possible for a long time, and we will work toward that goal. It's also possible that it may get harder to do things because of your illness, and I think it is important that we prepare for that*"[111]).

To meet patients' and family caregivers' needs to feel *seen* and *heard*, an individual approach is desired, with acknowledgment for the (emotional) impact of cancer on their lives. Methods to do this are first, providing space after giving medical information (gives the

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patient the opportunity to assimilate the information and respond[23,113]) and second, responding to the patients' emotions (e.g. using NURSE: naming, understanding, respecting, supporting, exploring[5,23]) and not ignoring them. Showing interest in the patients' life and building a relationship (e.g. "*I know all the medical details, but tell me more about who you were before this illness and how this has affected you and your loved ones.*"[5]) could also help. However, the need to be *held and remembered* goes one step further: entering into a relationship with your patient and then maintaining this relationship. Not meeting these needs could increase feelings of abandonment and make patients feel like a burden, especially when patients have poor prognosis.[61,114,115] This emphasizes the importance of reassurance that continuity of care is guaranteed (e.g. "*We cannot cure the cancer, but there is still plenty we can do and will do to help you, including helping you come to terms with this news. We will continue seeing you.*"[22]). Continuous support may become more challenging in the future as more people with cancer live longer[116] due to improved (experimental) treatment (which also increases mental burden[117]), expected decrease of clinicians[118] and increased use of digitalized healthcare systems.[119] Future research should focus on how to tackle this challenge, while still providing the best continuous support for patients and their family caregivers.

Within the context of the last two themes, a reflection on the distinction between harmful communication at the systemic level versus the individual clinician's level is needed. Clinicians need to know what they can do on individual level to avoid causing harm within the constraints of the system he/she is working in. For instance, our data illustrates that patients perceive "excessive waiting" (e.g. for test results) as harmful. Providing patients with a more concrete message while they are waiting can be helpful. For example,: "*We will call you between 4 and 5. If we have not called by then, you can reach out to us yourself*".[22] Additionally, literature indicates that insufficient time for conversations with the clinician is considered as unpleasant. This issue appear to be systemic and challenging for an individual healthcare provider to overcome. Nevertheless, literature demonstrates that small adjustments or behaviors can make a difference. For example, sitting instead of standing at the patient's bedside already gives patients the feeling that the consultation takes longer (without actually taking more time, possibly even less[120]). These approaches demonstrate that it is still possible to make a difference at the individual level.

4.2 | Limitations and future directions

Our systematic review has limitations. First, we only included English and Dutch papers and thus overrepresenting papers from the global north. Future studies could investigate the cross-cultural difference in information needs of patients and family caregivers, as these needs are expected to vary widely.[121,122] Secondly, due to the limited available data regarding the experiences of family caregivers, as compared to patients, it was challenging to draw distinctions between those two groups. This finding underscores the importance for future studies to conduct more in-depth research on the family caregivers perspective on harmful communication behavior. Thirdly, because many studies lacked data on disease stage, we were unable to make any determinations regarding a potential variation in harmful communication across clinical settings, which could be a valuable direction for future studies too. Lastly, we focused on clinicians' communication, while patients interact with many other healthcare staff. We do not know whether the same results would be found for other health care professionals or aligned staff. We cannot rule out that harmful communication behaviors reported in our study were expressed by others than clinicians themselves.

Since having difficult and emotional conversations with patients is a core task of clinician—which they feel untrained and ill-equipped for[123]– we hope this systematic review can provide clinicians with tools to have these consultations while preventing unnecessary potential harm. Communication trainings can assist to teach clinicians in avoiding these harmful communication behaviors and implement the helpful communication suggestions in clinical care, especially after studies have determined which behaviors have the greatest detrimental/beneficial effects on patient-reported outcomes. Until then we hope this systematic review will inspire clinicians to embed communication's power for the better and not the worse.

4.3 | Conclusions

Our results reveal a comprehensive overview of cancer patients' and family caregivers' perspectives on which clinicians' communication behaviors can harm. Harm could be prevented when information and decision involvement are tailored and patients' and family caregivers' needs to feel *seen*, *heard*, *held* and *remembered* are met. We hope this systematic review can provide clinicians with tools to communicate with patients and their family caregivers while preventing unnecessary potential harm.

AUTHOR CONTRIBUTIONS

Janine Westendorp: Conceptualization, investigation, methodology, project administration, analysis, writing–original draft, and writing–review and editing. **Olaf P. Geerse**: Conceptualization, analysis, and writing–review and editing. **Marije L. van der Lee**: Conceptualization, analysis, and writing–review and editing. **Jan W. Schoones**: Conceptualization, methodology, resources and writing–review and editing. **Milon H. M. van Vliet**: Conceptualization, methodology, analysis, and writing–review and editing. **Tamara Wit** Conceptualization, investigation, methodology, analysis, and writing–review and editing. **Andrea W. M. Evers**: Conceptualization, analysis, and writing–review and editing. **Liesbeth M. van Vliet**: Conceptualization, investigation, methodology, project administration, analysis, writing–review and editing, supervision.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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