SPECIAL ARTICLE

Communication and support of patients and caregivers in chronic cancer care: ESMO Clinical Practice Guideline☆

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INTRODUCTION

Communication is an essential component of health care. The existential threat of cancer, patients' support and information needs, evolving disease trajectories and increasing survivorship and the need for decision making about treatment options and trials in the context of rapidly developing therapeutic approaches, all put demands on dialogue between patients and health care workers.[1] Unsurprisingly, it has long been known that communication in cancer care is associated with medical and psychosocial outcomes, including distress and satisfaction for both patients and clinicians.[2-5] Consequently, it has become the object of training and research, demonstrating that some aspects can be modified.[6] This Clinical Practice Guideline (CPG) provides an up-to-date approach to communication with patients and caregivers in cancer care.

The nature of guidance for clinical communication

Compared with other clinical topics, guidance about clinical communication is a delicate matter. Firstly, communication is best learned in real life as it cannot be acquired solely by following protocols, attending lectures or reading.[7] Secondly, communication in cancer care covers diverse topics, including breaking bad news (BBN), conveying hope, shared decision making (SDM), cross-cultural communication and communication about advanced directives, medical errors, treatment side-effects and complementary and alternative treatments. For one guideline to cover all topics is impossible. Practicable guidance must therefore target cross-cutting communication issues.[8] Thirdly, communication, as stated in the 2018 European Position Paper on Training in Communication of oncology clinicians, cannot be conceptualised simply as objectively reproducible discrete skills.[7] As the meaning of communication is always context-dependent, universally correct or beneficial communication behaviours cannot be identified. For example, an open question to start a consultation is not always appropriate (e.g. if a patient anxiously expects tumour marker results). Similarly, patients do not always welcome empathic responses to their distress.[9] Communication quality therefore lies, not so much in performance of certain skills, as in clinicians' judgement as to when and how to use them. Fourthly, quantitative evaluation of specific communication behaviours is often clinically meaningless (e.g. the number of silences or empathic responses cannot indicate the quality of the communication).[8] Thus, statistically generalisable evidence about communication, necessarily based on quantification, has only a limited role in indicating quality.[10] Moreover, much quantitative research in this field, particularly on effects of communication training, has other conceptual and methodological weaknesses and often fails

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to assess effects on patients in real-world settings.[11] Fifthly, the right way to communicate does not just depend on evidence of its effects but is often an ethical matter. For instance, clinicians should involve, inform, respect and support patients because it is morally right, and not just to achieve certain outcomes.[12]

Further reasons for differentiating guidance for communication from that for more technical topics can be illustrated by considering aspects of the 2017 American Society of Clinical Oncology (ASCO) guidelines on clinician—patient communication which attempt to define ‘core communication skills’ and ‘specific communication skills’ for situations such as discussing goals of care and prognosis, treatment options or end-of-life care.[13] For each skill area, specific recommendations (>30) are provided and, for each recommendation, specific communication strategies are recommended (>100). While many strategies are valuable, two examples illustrate limitations of guidance that specifies behavioural strategies. The recommendation ‘When patients display emotion through verbal or non-verbal behaviour, clinicians should respond empathically’ is amplified by four strategies, including ‘Use partnership and supporting statements (e.g. “I want to make sure we do everything we can to get you the best outcome”)’. Such standardised statements can alienate patients, with recent evidence showing that patients feared that teaching doctors to follow communication protocols may lead to them appearing inauthentic.[14] Another recommendation concerns end-of-life care: ‘Clinicians should recognise and respond empathically to grief and loss among patients’. Expressions of grief or loss certainly demand responses, but before responding empathically, patients’ motivation for describing losses should be understood. For example, in a recent qualitative study of oncologist consultations, patients sometimes mentioned loss of a friend or family member to cancer after oncologists had remained unresponsive to previous patient cues inviting them to address issues of death and dying.[15] In such situations, empathy with the loss cannot be the sole communication ‘strategy’; oncologists should respond to the concern that was being conveyed by the evocation of loss.

Levels of evidence and grades of recommendation

For the reasons outlined above, guidance for clinical communication cannot comprise technical rules justified by quantitative evidence of their outcomes in randomised trials, or other designs relying on quantitative generalisation based on inferential statistics. Therefore, levels of evidence I-IV (see Supplementary Table S1, available at https://doi.org/10.1016/j.esmoop.2024.103496) are of limited relevance. Instead, a broader range of types of evidence becomes relevant, including in-depth qualitative studies that explore the meaning of communication in its context and that are inductive in seeking to identify general principles based on observation of specific instances of communication. Therefore, throughout this guideline the levels of evidence are V (see Supplementary Table S1, available at https://doi.org/10.1016/j.esmoop.2024.103496). Similarly, the strength of recommendations for clinical communication cannot be graded according to evidence of efficacy; therefore, recommendations are only stated where the authors are confident in their expert judgement, informed by the available research. Nevertheless, because communication is subjective and contextual, recommendations can only inform the judgements of clinicians in their practice and cannot provide hard-and-fast rules.

Recommendations that are strongly recommended (grade A) concern fundamental aspects of knowledge or attitudes underpinning the orientation that clinicians should take if they are to make good judgements (or that teachers of communication training and clinical supervisors should take to help clinicians do so). Recommendations concerning clinicians’ actions are generally recommended (grade B) because their implementation in specific situations will depend on individual clinicians’ contextual judgements.

Conceptualising clinical communication

There are different forms of communication in cancer care. Face-to-face communication includes verbal, non-verbal and para-verbal components allowing immediate interaction, feedback, clarification and mutual adjustment. Written communication is limited to unilateral messages. Finally, communication in social networks and mass media does not target specific individuals. This guideline addresses only face-to-face communication, taking an interactional and situated view, understanding that the meaning of every element of communication depends on its context, including the whole consultation, previous consultations, the individual patient and clinician, the immediate setting and broader culture. This contrasts with conceptualising face-to-face communication as a stimulus-response process mediated by sequences of speech such that when A says ‘X’, B says, or should say, ‘Y’. Very structured communication skills training or guidance, e.g. on including patients in trials,[16] sharing decisions[17] or BBN, reflect that ‘stimulus-response’ understanding.[16-19] The behaviours referred to as skills, such as making empathic statements, asking open questions or summarising what patients have said, only form part of effective communication. Using such ‘skills’ without an attitude of self-reflection, and without acknowledging each patient’s uniqueness, is inappropriate. Moreover, poor judgement about which behavioural skills to use and when to use them could lead to a technical approach resembling a speech robot. Conversely, without adequate communication behaviours, health care workers with an appropriate attitude could be helpless or unprofessional. Some clinicians, for instance those lacking relevant experience, might initially find a structured protocol helpful. However, clinicians will need the right behaviour, attitude and judgement if they are to adapt to individual patients’ needs.

What makes communication satisfying for patients and clinicians depends heavily on individual clinicians’ characteristics: their ability to imagine patients’ feelings and needs; their capacity to ‘stay with’ the suffering patient without coldly defending themselves against their own painful emotions; their spontaneity, creativity and motivation; and their biography, professional competence and experience.[9] Both patients and clinicians value authenticity.[20] Clinicians describe learning how to communicate by immersion and reflection in clinical practice, by watching others or by participating in training, and progressively internalising ways of communicating until these ‘feel right’ for them.[21] Therefore, our recommendations are not primarily at the level of behaviours, but emphasise knowledge and attitudes that can help practitioners make good judgements in their communication. Figures 1-3 summarise the recommendations with their main implications for clinicians, oncology teams and the institutions that host oncology services.

Recommendations

- Teachers of communication training, clinical supervisors and clinicians should understand that communication is more than deploying skills but depends also on the knowledge and attitudes that guide clinicians’ judgement about how to communicate in any instance [V, A].
- Teachers of communication training, clinical supervisors and clinicians should pay special attention to factors related to the individual clinician and patient which shape communication needs and solutions in specific instances [V, A].
- Teachers of communication training and clinicians should be aware that learning to communicate with patients is an individual process, so the training format should allow adaptation to learners’ individual needs (e.g. small group training, supplemented by individual supervision) [V, A].

BACKGROUND ISSUES OF PATIENT—CLINICIAN COMMUNICATION

The psychology of the patient

Being an oncology patient is framed psychologically by the vulnerability inherent in having, or fearing, a potentially mortal disease and by the emotional challenge of confronting a new reality in which that disease and its treatment can overturn assumptions and expectations for the future. Vulnerability is therefore the context for clinical communication in oncology. Attachment theory provides a helpful theoretical framework for understanding how patients’ vulnerability shapes communication needs.[22-24] Attachment theory is a psychological, evolutionary and ethological theory, which states that humans need to develop a relationship with at least one person for normal social and emotional development; otherwise, as in the case of severe neglect, children may show avoidant and anxious attachment, and as adults feel insecure even in relationships with competent and adequate carers such as clinicians. It is based on clinical observation and empirical evidence that children and adults respond to vulnerability by seeking a close relationship with a person whom they see as able to protect them. In oncology, that ‘secure base’ is typically the clinician; so vulnerable, newly diagnosed patients can feel an intense relationship with their clinician even after one brief meeting, based on trusting their clinician’s expertise and conscientiousness.[25] Attachment theory also suggests that a person’s ability to develop confidence to function independently depends on having a secure base, so it also has implications for longer-term self-management of illness and treatment. From an attachment perspective, clinicians can have a challenging task in ensuring that clinical decisions respect patients’ own values

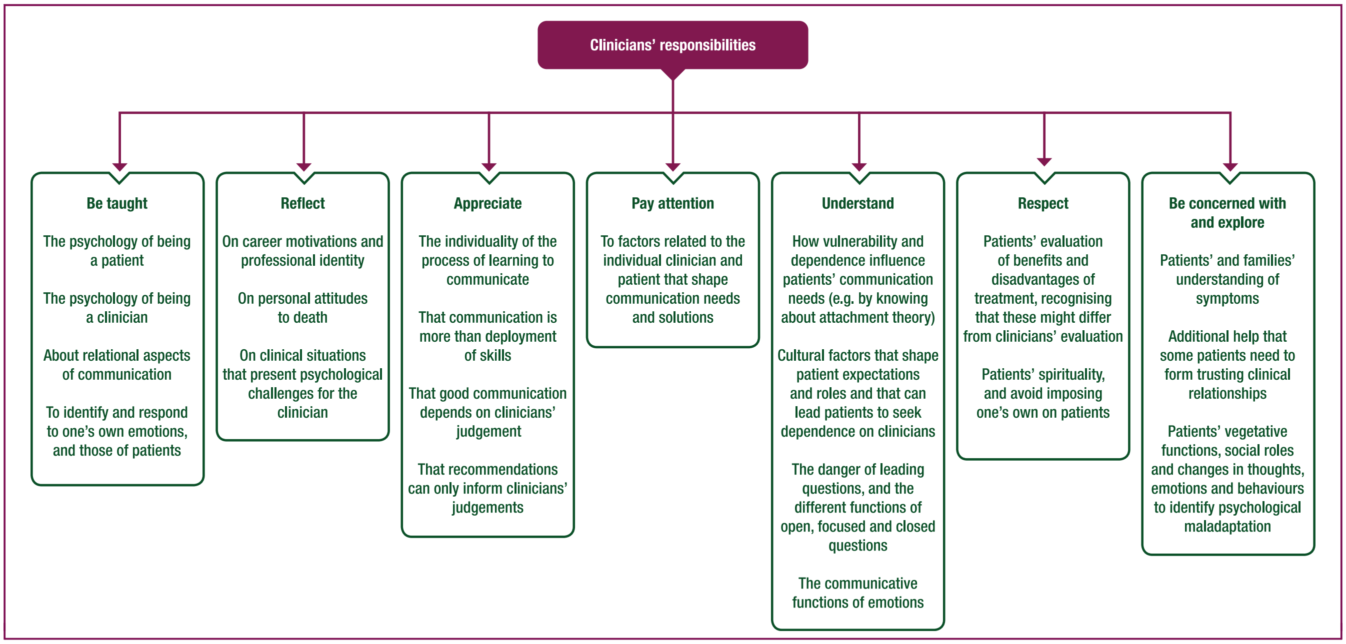

Figure 1. Ensuring good judgement in clinical communication: clinicians’ responsibilities.
Purple, algorithm title; white, other aspects of management.

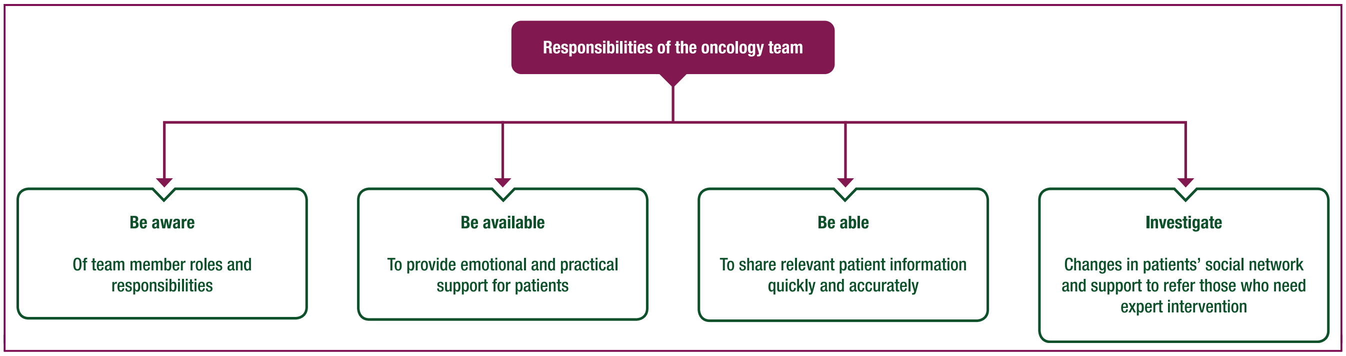

Figure 2. **Ensuring good judgement in clinical communication: the responsibilities of the oncology team.** Purple, algorithm title; white, other aspects of management.

and preferences, because patients' need to trust clinicians will mean that many do not ask questions, and do not seek information or involvement in treatment decisions. Moreover, many patients cope with the threat of an uncertain or curtailed future by focusing on day-to-day matters, trusting clinicians to take responsibility for the longer term and to decide what patients need to know and when.[26,27]

The challenge for the clinician is further increased by the social construction of medical care, which ascribes different roles to clinicians and patients. To consult a clinician, a person is expected to adopt the patient role while the clinician takes the role of a knowledgeable and authoritative helper. Faced with patients who, whether for psychological or cultural reasons, do not assert their own needs, paternalistic medicine would impose clinicians' own preferences and values on their patients. Instead, clinicians must recognise patients' need to place their trust in a caring clinical relationship, while identifying and respecting the needs and values that patients might not freely volunteer.[28]

Phases of emotional distress, denial and intensive mourning are frequent and normal reactions to cancer diagnosis. The rhythm of this psychological cycle may not always synchronise with somatic changes and treatment requirements, and this can complicate communication. For example, it is difficult for patients to hear and understand information while in denial or to make decisions when despair prevails. If clinicians recognise when patients are not in phase with the clinical situation, they can adapt their communication, even delaying communication objectives. Whereas some clinicians facing such communication challenges might intensify or repeat medical messages, clinicians attentive to patients' psychological world could briefly leave the medical agenda and acknowledge or explore that personal world.[1] For example, it is not constructive to explain the advantages of a treatment to a patient, recently informed of relapse, who states "I've had it, there's no way I can undergo that again". Instead, the patient's words can be understood, not as information in a biomedical dialogue but at an emotional level as expressing disappointment. A possible answer would be that "I can understand your disappointment after having endured side-effects and having hoped for a cure, now suddenly discovering that cancer

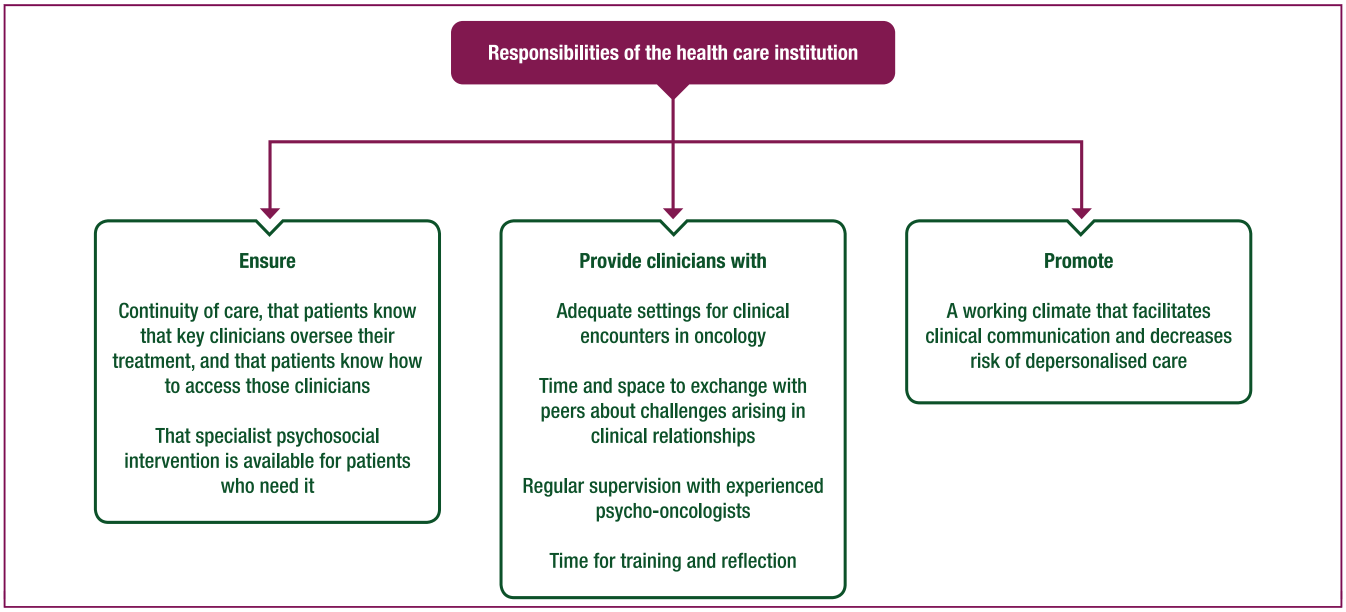

Figure 3. **Ensuring good judgement in clinical communication: the responsibilities of the health care institution.** Purple, algorithm title; white, other aspects of management.

has returned”, with time for the patient to respond if wished. Only once disappointment is expressed and acknowledged would the question of what to do next be addressed.

Details on supporting patients who show signs of psychopathology and who need psychiatric assessment and treatment are described in the ESMO CPG on anxiety and depression in adult cancer patients.[29]

The psychology of the clinician

Psychological challenges for oncology clinicians arising from their practice can interfere with communication.

Cancer patients are often unavoidably harmed by their care, for example the psychological effects of diagnosis or the physical side-effects of treatments. Clinicians’ identity, however, rests on motivation to prevent or reduce harm, and their choice of profession may even be influenced by their own experience of suffering.[30] Clinicians, therefore, must cope with the harm experienced by patients, especially when this is inflicted by medical care; however, knowing that they are inflicting harm can provoke anxiety, guilt and shame, or other painful emotions. These responses might lead clinicians to avoid communication about sensitive issues such as patients’ disappointment about relapse or persistent side-effects of treatments. Disappointment is a frequent experience in oncology, shared by patients and clinicians. For clinicians, disappointment can be amplified by the impression of not having reached professional and personal ideals (e.g. always cure). Such situations and repeated feelings of disappointment may lead to burnout and emotional detachment, hampering encounters with patients.

Experiencing limitations to medicine’s power is unavoidable in oncologists’ daily practice. Associated feelings of impotence may lead to feelings of desperation, frustration and anger. When the patient experiences the same feelings, the emotional atmosphere can become unbearable. This has consequences; e.g. clinicians may restrict communication with patients to essential biomedical aspects of care, or propose anticancer treatments when discussion of transition to palliative care would be more appropriate.[31]

Since patients experience many threats and losses during the cancer journey, anxiety and sadness are prevalent emotions. They are contagious and can resonate with the clinician. While such resonance can promote empathy, if clinicians are overwhelmed by these feelings, they can no longer offer the patient a ‘secure base’.

Finally, death of other patients, and awareness of their own impending death and separation from loved ones, can provoke emotions in patients (particularly anxiety), which are difficult for clinicians to face. Clinicians’ own biographical experiences may be echoed by their patients’ end-of-life situations and can distort communication and even treatment decisions.[32] If the echoes from clinicians’ past are intense (on conscious or unconscious levels), it can direct communication towards serving their own needs, perhaps blocking empathic exploration of patients’ suffering.

An integrated bio-psychosocial and spiritual orientation

An integrative orientation, encompassing biological, psychological, social and spiritual aspects of disease can help clinicians to build clinical relationships, promote trust and identify unmet needs. The dimensions which clinicians should investigate depend on individual patients’ situation and phase in the cancer trajectory. For example, in early treatment phases, efficiently and conscientiously initiating treatment will be the essential component of ‘being with the patient’ while, in end-of-life care, psychosocial and spiritual dimensions will need more attention. Clinicians should perceive patients’ needs and respond appropriately.

Biological dimensions of illness. Clinicians’ explanations of the disease and symptoms help patients adapt to their situation. Identifying and correcting patients’ and relatives’ misunderstandings is essential (e.g. explaining fatigue as an expected consequence of radiotherapy rather than as indicating disease progression). Symptom expression can convey more than biomedical information; e.g. symptoms may be magnified by emotions, or coloured by patients’ beliefs about the body, or can be a clue to relational needs.[33] Therefore, responding to symptoms may require clinicians to go beyond purely biomedical understanding. Moreover, symptoms affect patients’ daily living, e.g. reducing mobility and changing patients’ experience of space as their world shrinks. Exploring how symptoms affect patients is also a way to join them in their experiences and to foster the clinical relationship. Finally, the subjective meaning that patients attribute to physical symptoms and bodily changes may affect their view of themselves (e.g. when incontinence is experienced as shameful regression to childhood).

Psychological dimensions. It is more important to identify disturbance that needs further investigation (and specialist referral) than to gain extensive overviews of patients’ psychological state. Distinguishing between normal reactions and psychiatric disorders is, however, difficult. Psychiatric disorders often affect patients’ vegetative functions (e.g. appetite, sleep, digestion) and social roles (e.g. as parent, professional, friend), but for patients with cancer these can also be modified by disease or treatment. Where unrelated to cancer and its treatment, modification of vegetative functions and social roles may be prodromal signs of psychopathology.[29] A patient’s or family members’ feelings that the patient has radically changed regarding thoughts, emotions or behaviour (e.g. outbursts of anger in a previously calm person) may suggest psychopathology. Generally, normal cognitive and emotional states contribute to people’s adaptation, while pathological states do the opposite (e.g. fear of cancer recurrence might serve, if not too intense, to maintain vigilance and prompt consulting, whereas panic can paralyse patients or delay consultation). Identifying patients who might benefit from additional support by oncology staff or specialist referral is a subject of ongoing research and debate.[34,35] If screening instruments are used (e.g. General Health Questionnaire, Hospital

Anxiety and Depression Scale or Rotterdam Symptom Checklist), results should be interpreted in the context of dialogue with the patient.[28,29,35,36]

Social dimensions. Clinicians should be alert to patients' social context. Given the practical and emotional challenges of cancer and its treatment, patients should benefit from practical and emotional support from their social networks. However, some patients are socially isolated, and cancer can strain or rupture relationships, adding to patients' burden. Feelings of shame and self-blame associated with cancer can compound patients' difficulties in drawing support from others. Moreover, cancer can lead to stigmatisation (especially those such as head and neck cancers related to substance abuse), and loss of employment and income. Where social networks cannot provide sufficient support, further assessment and expert intervention (e.g. to help patients obtain financial or practical support) will be necessary.

Spiritual dimensions. See also ESMO Guidelines on care of adult cancer patients at the end of life[37]; in addition to the observations made therein, spiritual and existential issues are highly individual.[38] Clinicians should therefore be open to patients who wish to voice or discuss these issues and avoid applying their own beliefs and hopes to patients.

Setting of the consultation

The setting encompasses the intervals between consultations, the time allotted, the physical space, including its layout and porosity (intrusions from outside, such as phone calls) and presence of third parties (e.g. the patient's partner or accompanying person), all of which affect communication. The setting in which nurses practice might be especially challenging (e.g. presence of other patients, busy hospital atmosphere). Given this complexity, universally applicable rules regarding settings do not exist. Frequency and duration of consultation should not be fixed but should depend on the patient's physical and psychological needs; flexibility regarding duration is often in competition with the objectives of the institution, which is preoccupied by patient flow and clinical productivity. Before meeting a patient, the clinician should have reflected on the adequacy of the specific setting for the meeting and on how it serves or impedes the communication goals.[39]

Video consultations are a specific setting; although acceptable to patients and oncology clinicians, their effects on care have rarely been assessed.[40] Consultations over the phone are inadequate when difficult decisions or announcements have to be made. During the coronavirus disease 2019 (COVID-19) pandemic, guidelines for effective and safe online consultations were developed.[41,42]

The broader health care context

Contextual factors, although rarely the subject of teaching and research, or identified and addressed in clinical settings, shape clinical communication.[7] For instance, institutional routines and resources constrain clinicians (e.g. precluding time for SDM to unfold), use of computers reduces eye contact, etc. Patients, similarly, must follow rules and adapt to the organisation of medical care, sometimes leading to frustration which can be directed towards clinicians.[43] Hospitalised patients, in particular, are confined to defined spaces with loss of privacy, and lives governed by institutional priorities (e.g. meal and medication times) and unexpected appointments and procedures, all of which can induce feelings of powerlessness that can disrupt relationships with clinicians, e.g. when manifest as anger.

Dominant discourses circulating in society can also influence communication by shaping patients' or clinicians' attitudes or expectations. For instance, patients and their families can perceive the popular metaphor 'war against cancer' as an injunction to adopt a fighting spirit, while patients might prefer to trust to treatment or submit to fate.[44] Similarly, mass or social media representations of oncology and its therapeutic possibilities foster unrealistic expectations which can damage communication (e.g. when angry patients, influenced by unrealistic portrayals of new anticancer treatments or even fake news, deplore their oncologists' apparent powerlessness).[45]

Recommendations

The psychology of the patient.

- Clinicians should be aware of the psychological and cultural reasons why patients often seek dependence on clinicians instead of taking an active role in decisions about care [V, A].
- Clinicians should be taught about the psychology of being a patient, and about how this knowledge can guide communication [V, A].
- Attachment theory can be a helpful framework for educators and clinicians to ground clinical communication in an understanding of the feelings of vulnerability associated with being a patient [V, B].
- Clinicians should be concerned with patients' psychological state, identifying patients who are psychologically not in phase with medical reality (e.g. significant denial), and adapting communication accordingly [V, B].

The psychology of the clinician.

- Clinicians should reflect on their career motivations, professional identity and attitudes towards death, and identify how clinical situations of uncertainty, impotence, disappointment or loss present psychological challenges potentially influencing their communication with patients [V, A].
- Institutions should provide time and space for clinicians to exchange with peers about the challenges faced when treating patients and to reflect on their attitudes, thoughts and emotions through regular supervision with experienced psycho-oncologists [V, A].
- Training in communication should address the psychological challenges that clinicians encounter in oncology [V, A].

An integrated bio-psychosocial and spiritual orientation.

- Clinicians should explore patients' (and relatives') understanding of symptoms, be attentive to how patients experience bodily symptoms, understand that patients' symptom expression may convey more than biomedical information and be ready to respond with information or emotional support as necessary [V, B].
- Clinicians should investigate patients' vegetative functions, social roles and changes in thoughts, emotions and behaviours to identify psychological maladaptation to the disease, and to identify needs requiring expert intervention [V, B].
- The oncology team needs to be aware of changes in patients' social network and support and investigate any apparent deterioration to identify patients who need expert intervention [V, B].
- Clinicians should respect patients' spirituality and avoid imposing their own on patients [V, B].
- Clinicians can consult the ESMO Guidelines on the care of adult cancer patients at the end of life for detailed recommendations [V, B].

Setting of the consultation.

- Clinicians need to know that the setting influences clinical communication, to reflect on the suitability of available settings, and to be able to select or shape settings to facilitate communication [V, A].
- Clinicians using video consultations should familiarise themselves with existing guidelines on their use [V, B].

The broader health care context.

- Institutions should guarantee the adequacy of settings for the range of clinical encounters in oncology, especially regarding allocated space and time for consultation [V, A].
- Clinicians should understand how cultural representations of oncology can shape the expectations that patients bring to consultations, and they should be alert to these potential influences in individual patients [V, A].

COMMUNICATION ISSUES THAT APPLY TO ONCOLOGY CONSULTATIONS IN GENERAL

Structure of the interview

Structuring the interview helps clinicians not to forget important information and patients to remember the conveyed information. Structure can be established by agenda setting, agreeing priorities for discussion and by following a certain logic (e.g. present results of investigations, then their significance for the patient's treatment). Communication can also be structured by regularly summarising information, checking comprehension or prompting questions before announcing what will be discussed next. Overwhelming focus on structuring conversations may have negative effects, such as excluding spontaneous talk.[46]

Obtaining and providing information

Obtaining and providing information are important goals of communication in cancer care. The presence of a 'significant other', if the patient wishes, facilitates information exchange, as does the clinician's respectful attitude.[47] Language barriers must be considered when obtaining and providing information; a family member speaking the clinician's language may be of help but is not optimal (e.g. shame to speak about certain issues in front of a family member, wish not to burden); a staff member or clinician over videoconference speaking the patient's language is the best solution to diminish the negative impact of language barriers, followed by assistance by interpreters.

Obtaining information is facilitated by explaining the rationale for questions when not self-evident, by normalising emotional reactions and by reminding patients of medical confidentiality when addressing sensitive issues such as sexuality or family dynamics. Depending on the objectives of information gathering, different types of questions are used. Open questions such as "how do you feel" provide room for patients to speak freely; focused questions such as "how was the pain since you started the new medication" help to circumscribe a medical issue, as do closed questions such as "did you suffer from headaches during the last week". Leading questions pointing to specific answers (e.g. "the pain improved, right?") should be avoided.[48] Linguistic conventions of conversation mean that many apparently open questions can be 'leading' in that they make some answers more likely than others. For instance, in native English-speaking patients, asking "is there something else you want to address today" is more likely to elicit unmet concerns than asking "is there anything else you want to address today".[49]

Providing information has many functions. It allows patients to adjust to illness, to comply with recommendations, to anticipate and mourn losses, to understand treatment and treatment options, to plan the future and to participate in decisions. It can also help them to (re)gain a sense of control or hope and trust in their clinician.[50] When patients have already been informed about certain aspects of their disease, it has been recommended that clinicians first explore their understanding of the medical situation when providing new information.[48] This allows clinicians to adjust new information to patients' existing knowledge and understanding, and to avoid repeating what is already known. However, clinicians may refrain from exploring existing knowledge when patients need them to come to the point quickly. Moreover, patients should not experience such exploration as a test.

Providing information sometimes consists of BBN (diagnosis, worsened tumour markers, treatment resistance, etc.). While structured and scripted protocols such as SPIKES can help clinicians who seek detailed guidance, it is not clear that they necessarily meet patients' needs.[18,51,52] In practice, bad news is often complex and unpredictable, reflecting patients' subjective perception of information, and unfolding over time rather than being acquired on a single occasion.[53]

Since patients information needs differ, clinicians may ask how much detail a patient wants; however, patients who request all available information sometimes later complain of receiving too much.[54] Moreover, patients cannot know what they want to hear until they know what there is to be told. Therefore, clinicians must gently explore what information patients want to receive, being sensitive to cues indicating whether and when they are ready for more.[55] With patients who do not wish to be even minimally informed, or who show ambivalence, the clinician can explore their reasons (e.g. severe anxiety, misunderstanding or denial) without pressuring them to modify their stance or appearing to disrespect it. The issue of whether and how significant others ought to be informed should also be clarified with patients when providing information. A patient's expressed wishes regarding information needs may vary depending on the interlocutor; nurses play an important role in this respect as mediators and advocates of the patient.

When providing complex information, clinicians should proceed in a structured way (see also 'Structure of the interview'). The 'book metaphor' can help. First address the title, then the chapter and subtitles: "The investigation of the lump in your breast revealed it to be a cancer (title); today I will tell you about treatment options (chapters); first, chemotherapy (subtitle of a paragraph)". Pauses between steps can help patients process the information and can show that the clinician understands that the information might be difficult to absorb and can provide space for questions or expressions of emotion. Moreover, pauses allow clinicians to assess the information's impact (e.g. when patients show shock, further information might not be absorbed). Because patients' recall of information is limited, especially when anxious, prioritisation (What is most relevant for this patient to know today?) is crucial, as is language that avoids jargon and is adapted to patients' understanding.[56] Written material, metaphors and illustrations, as well as tools (readily available online) which pictorially illustrate and complement the verbal information can help.[57] Nevertheless, information tailored to each patient in the context of a trusting relationship is more valuable than general information provided anonymously, e.g. by leaflets.[58,59]

Invitations to ask questions can be introduced by explaining that misunderstanding or incomprehension can arise because the clinician might have inadequately translated highly specialised medical information, and that the patient should not hesitate to seek clarification. It could also be helpful to state that difficulties in understanding are normal in this situation.

Explaining options and making decisions

Decisions about care and treatment should respect not just patients' clinical needs but also their wishes and values, such as the value they attach to small probabilities of clinical benefit from continued treatment versus the morbidity associated with noxious treatment. The concept of SDM was developed to ensure that treatment decisions accord with patients' needs and values by involving patients in those decisions.[60] There is useful guidance on how to involve patients: by ensuring that they know that options exist, that they know the important outcomes of each option and consequences of doing nothing, and that the clinician helps them deliberate before reaching a decision.[61] However, patients' ability to represent their own interests by actively participating in decisions is often limited by their emotional state, their adoption of a 'patient role', the technical complexity of biomedical knowledge and their discomfort with feeling responsible for decisions (see 'The psychology of the patient'). Therefore, involving patients requires clinicians' careful judgement; they should assess patients' readiness or ability to make decisions, then lead decisions or invite patients to make them according to that assessment and according to the clinical consequences of the proposed options.[28] For instance, where clinical benefits of a treatment clearly outweigh any negative effects, and there is minimal uncertainty about those consequences (e.g. radiation or corticosteroid for spinal cord compression due to lymphoma), lengthy decision-making discussions are unnecessary unless patients decline treatment, in which case clinicians should explore their reasons and correct any misunderstandings. Uncertainty is, however, common in oncology and must be acknowledged in consultation. Clinicians will convey the uncertainty (see 'Obtaining and providing information'), then engage the patient in SDM according to their assessment of patients' ability and willingness to participate or to be advised by their clinicians. Since patients may feel ambivalent towards certain treatments, given associated toxicities or fears, techniques of motivational interviewing can help and might improve adherence to treatment.[62,63] Similarly, techniques of argumentation can help clinicians to lead decisions.[28] When clinicians do lead decisions, they should prompt for patients' reactions, since patients might be unhappy with their recommendations.

SDM is often considered as a 'zero-sum' situation whereby, if clinicians take more responsibility, patients take less. In practice, however, patients can feel involved in clinicians' decisions if clinicians explain their reasons.[64]

Responding to emotions

Emotions influence thinking, understanding, memory and decision making. Emotions are also signals, both to those experiencing them and to people around them. For example, fear signals a threat from within the person such as an unwanted thought, or from outside such as disease. Sadness signals loss, rage an injury or obstacle, shame a feeling of falling short of some standard. Surprise signals something unexpected, disgust something to avoid. Therefore, patients' emotions have communicative functions which can foster clinical relationships when clinicians perceive, understand and acknowledge them. Conversely, when significant emotions remain undetected and unaddressed, they can continue to express themselves through attitudes or non-verbal behaviours (e.g. patients' anxiety may manifest as repeating questions without integrating clinicians' answers, or clinicians' anxiety can manifest as avoiding sensitive issues by focusing on biomedical aspects). Responding empathically to emotions, however, can foster relationships, especially if the reasons for the emotions are understood. This is not always easy. Empathically telling a young man, upset about diagnosis of testicular cancer, that "I understand your distress" is premature without first clarifying the cause of the distress (e.g. fear of cancer, thoughts of losing fertility or anger about treatment disrupting his career). Clinical judgement must therefore lead clinicians' responses to patients' emotions; in some situations, clinicians will convey hope or reassurance; in others they will clarify underlying concerns or provide instrumental responses (e.g. investigation and treatment of a symptom); in others, they will engage empathically with patients' emotional distress. Different responses may operate simultaneously. Instrumental responses relying on the therapeutic possibilities of medicine are important but relying solely on these can create difficulties when medical power is limited and disease progresses.

Patients' emotions can be difficult for clinicians.[65] Clinicians' 'blocking' behaviour such as changing from emotional to medical topics is common. Among the challenges for clinicians when patients are emotional is their own fears of the 'irrational', of not 'knowing what to say' or of having no immediate comforting solution. Emotions do not, however, always demand action, rather acknowledgement that the clinician has perceived the emotion and, if the patient wishes, is ready to hear more. Rather than premature closure or reassurance ("I understand", "Don't worry, it will be OK"), a silent pause can indicate recognition and acceptance of what the patient has expressed and thereby decrease feelings of isolation. Similarly, remaining silent and concerned in face of patients' suffering can be more reassuring than general statements such as "we will do everything we can to maintain your quality of life" or "we will not abandon you". It is, after all, for patients to judge what is a good quality of life or when they need support from staff.

Relationship building and support

Meeting patients' needs for a 'secure base' (see 'The psychology of the patient') depends on clinicians' effective engagement with patients, which has multiple elements. Specifically, patients value clinicians who act quickly, are punctual and decisive, do what they have promised, ensure efficient information flow within the care team and institution and are attentive, focused and reliable, responding appropriately to patients' emotions and valuing patients' own resources, as providing a sense of security at a time of loss or uncertainty.[66]

Of course, it is not always enough for clinicians to simply be available as conscientious, authoritative attachment figures. Their communication is also important in establishing, maintaining or developing trusting relationships. To feel supported, some patients need the opportunity to express feelings and concerns, and different team members can take different roles in this respect. Nurses, who sometimes see patients intermittently over longer periods of time, play an important role in identifying patients who are in distress or have unmet needs. Patients value continuity of care. While this is often difficult to organise, patients may appreciate knowing that a key clinician oversees their care or how to contact the team with questions or concerns. Moreover, a well-functioning team can itself provide a 'secure base'.[67]

In the asymmetric relationship created by their vulnerability and dependence, patients typically see clinicians as authority figures with power and expert knowledge. In this context, attachment theory (see 'The psychology of the patient') helps to understand that patients' experience of clinical relationships can depend on their previous experiences of care. Having been raised with loving and attentive caregiving equips patients to trust clinicians and to feel valued and supported as patients. Conversely, previous negative experiences of care can leave patients suspicious and sensitive to clues that clinicians might not conscientiously care for them (e.g. interpreting a clinician who forgets to call with promised results as uncaring). Communication with clinicians can be particularly difficult for patients with histories of abuse or neglect that have left them avoidant or fearful of closeness in relationships. Such patients can appear 'hard to reach' or even hostile and require more time and patience based on understanding that their attitudes are rooted in past experiences.[68]

Psychological support, unlike practical support, does not necessarily strive for solutions (which might be unavailable) but for understanding which reduces patients' sense of isolation and abandonment. Feeling pressured to find 'solutions', or to 'treat' patients' distress, may lead clinicians into feelings of impotence which, in turn, lead them to avoid patients' concerns. Where patients' experience resonates with clinicians' own experience or unresolved issues (e.g. regarding separation or powerlessness), clinicians might avoid certain issues or, alternatively, become excessively involved.[69]

For patients affected by psychiatric disorders (pre-existing, due to cancer or its treatment, or arising independently from the disease), referral to psycho-oncology clinicians who are integrated members of the oncology team might be beneficial.

Supporting hope

When addressing diagnosis, treatment or prognosis, cancer patients want clinicians to tell the truth, but also to help maintain hope.[70] Many physicians fear these discussions, or feel torn between adequately informing patients and damaging hope or admitting their own uncertainty.[71] Step-by-step pairing of bad news with reassuring information (e.g. by underlining that there are means to control the cancer or to alleviate suffering), or with information about treatment or care, can maintain hope without disguising the seriousness of the situation.[72,73] Exploring patients' wishes for the future may help to identify and support their hopes (e.g. to participate in a forthcoming anniversary). Rather than being reduced to simple techniques, however, communication to maintain hope should be seen as a collaborative, bidirectional process between physician and patient in which patients' ability to be hopeful is intimately connected to their ability to entrust themselves to clinicians' care.[54,55,58] Moreover, helping patients to remain hopeful requires clinicians to understand, not only their aims for the future, but also their wish at times not to think about the future.[27]

Interprofessional communication

Nurse-led interventions, alone, can improve outcomes such as patients' activation, self-efficacy, health literacy and quality of life, and joint physician—nurse meetings with patients can be helpful, reflecting the professions' complementary competences.[74] However, the growing complexity of cancer care requires the involvement of a broader range of professionals. Interprofessional collaboration helps to optimise care and, if efficient and timely, provides the patients with a sense of having a well-functioning care system that can provide a 'secure base' (see 'The psychology of the patient'), but poor communication has been identified as the greatest barrier to interprofessional collaboration.[75] Multidisciplinary tumour conferences are well established as improving collaboration, especially for treatment recommendations, decision making and care coordination, and can improve patients' health-related quality of life and survival.[76] However, non-medical professionals' participation can be limited by the pace of discussions, spatial layout prioritising clinicians, perceptions or self-perceptions of lower status or uncertainties about their roles.[77] In recent years, interprofessional communication training programmes for oncology teams have begun to emerge.[78]

Chronic cancer and survivorship

Oncology has undergone major transformations over the recent decades. Increasingly, cancer can be cured or becomes a chronic disease. Together with its increasing incidence, this leads to more patients surviving cancer.[79] Cancer survivors have multiple physical, psychosocial and supportive care needs such as sequelae from treatments, fatigue, altered sleep and cognition, fear of recurrence, effects on intimacy and sexuality and financial, employment and rehabilitation difficulties. Unmet needs in these areas are associated with anxiety, depression and reduced quality of life.[80] Patients might also need to take on responsibilities around surveillance or lifestyle changes. Moreover, after completing treatment, people close to patients often want to 'close this chapter and move on', while patients still struggle with physical or psychosocial consequences of cancer and its treatment. Clinicians must therefore remain attentive to changing needs of patients and family throughout treatment and follow-up. Screening tools such as the Distress Thermometer might help to inform communication with practitioners.[81] Since traditional oncology services often do not adequately meet these needs, alternative models have been proposed, such as general practitioner- or nurse-led care, in which oncologists are included when necessary.[82] Survivorship care can therefore be impaired by inadequate communication within the health care team.[83] Patients who were treated for cancer during childhood or adolescence need special attention; here, there is a significant risk of fragmentation of care, and particular need for effective communication between patients, parents and the clinical team, and between team members, especially when these patients are referred to adult services.[84] The implementation of survivorship care plans has thus been recommended (e.g. ASCO Survivorship Care Guidelines, Care Plans and Resources).[85]

Meetings with family or significant others

Meetings with families and significant others can provide information, achieve shared understanding of patients' situation, enlist families' help in managing or supporting patients, particularly in the palliative phase, and elicit individuals' needs, including for support or specialist psychological or social intervention. Such meetings, always conducted after having obtained patients' consent, are also opportunities to identify and address problems with family functioning or cohesion, and with family hierarchies and roles, which can all be challenged by the disease and its treatment. For example, meetings can help to identify damaging family dynamics (e.g. disagreements over therapeutic objectives or conflicts over roles), indicating that a family needs specialist help with communication and conflict resolution. At the beginning of a meeting, it helps to set the agenda, to name the issues that participants wish to discuss, to identify their understanding of the patient's situation and to elicit their expectations of the meeting. It is helpful to conduct family meetings with another staff member (e.g. nurse, social worker) subject to their involvement being explicitly agreed and, if necessary, negotiated with the patient and family. General information on how to encounter families is available.[86,87] Family meetings must be planned (by consultation between oncology professionals who will conduct the meeting). Managing the meeting includes: orienting the family to the meeting's goals; checking individual members' understanding concerning the illness and prognosis and their consensus regarding goals of care; identifying their concerns and views about the future; and identifying their emotional state, coping resources and commitment, and the support available to them. For patients who are parents of young children, see the review by Semple and McCance and, for spousal caregivers, see the review by Li et al. and the specific NICE guideline.[88-90]

Family members or other people who help the patient may sometimes interfere with patients' best interests or medical care. Clinicians must respect patients' privacy, but also have a moral obligation to protect patients who are vulnerable and dependent. If there are indications that people surrounding the patient might have a negative impact, these issues should be addressed, first with the patient and then with the person concerned. Legal, ethical and deontological frameworks can provide guidance in such situations.

Recommendations

Structure of the interview.

- Initial agenda setting, including agreement on topics to be addressed, and a coherent interview structure including regular summarising and breaks for questions, can help clinicians to manage the consultation and enhance patients' information recall [V, B].

Obtaining and providing information.

- Clinicians should be aware of the danger of leading questions, and of the different functions of open, focused and closed questions, which they should be ready to use at appropriate points in a consultation [V, A].
- Clinicians should carefully manage information-giving, observing patients closely as they provide information to gauge what they are ready to hear, and when, and how they are experiencing the information [V, B].
- Regular pauses during dialogue allow clinicians to perceive the psychological impact of information and give patients opportunities to react, express emotions, ask questions and assimilate the information [V, B].
- Clinicians should structure information, avoid medical jargon and check understanding; when appropriate, accompanying written material and illustrations can complement verbal information, especially when tailored to the patient and given in the context of the clinical relationship [V, B].

Explaining options and making decisions.

- Clinicians should be aware that patients' evaluation of the benefits and disadvantages of treatments might differ from their own, should respect and understand these evaluations and should be ready to address them where clinically appropriate [V, A].
- Clinicians should be aware of the psychological and cultural reasons why patients might not readily express their own preferences [V, A].
- Clinicians will often need to recommend treatments to patients where the clinical benefits are clear and in line with patients' goals for themselves [V, B].
- Where there is uncertainty, including about the extent of treatment benefits or harms, or their significance for the patient, clinicians should: acknowledge that uncertainty; assess the patient's ability and willingness to take part in treatment decision making; and lead decision making to the minimum extent necessary to ensure a decision that is in line with the values and goals that the patient has for himself or herself [V, B].
- Where patients wish to participate in the decision, clinicians should ensure that patients know the options that are clinically and practically available and their consequences and should help patients deliberate about the options [V, B].
- Where clinicians recommend treatment decisions to patients, they should prompt patients for their reactions to check for acceptance, misunderstanding or concerns [V, B].

Responding to emotions.

- Clinicians should understand the communicative functions of patients' emotions [V, A].
- Because barriers to clinicians' empathic responses to patients' emotions are often linked to clinicians' own unease with emotions, clinicians should learn how to identify and respond to both their own and patients' emotions as part of their training [V, A].
- For a clinician to respond appropriately to patients' emotions means knowing, or exploring, what provoked the emotion, before judging the appropriate response: for example, conveying hope, clarifying medical issues, responding empathically or further exploring underlying concerns [V, B].

Relationship building and support.

- Institutions and training providers should provide time for clinicians' reflection on barriers to engaging with patients, including clinicians' own unresolved issues that might resonate with a patient's situation [V, A].
- Clinicians must be alert to the ways in which some patients' history of caring relationships leaves them unprepared to form trusting clinical relationships and must be ready to offer such patients appropriate help to feel valued and to be able to trust their clinicians [V, A].
- To establish the foundation of trusting relationships, clinicians should ensure clinical engagement with patients that is efficient, authoritative and conscientious [V, B].
- All members of the clinical team should be available to provide emotional support, based on patients being listened to and understood, although the extent of their supportive role can vary between team members [V, B].
- Institutions should do their best to ensure continuity of care. Where this is impossible, institutions and clinicians should ensure that: patients feel safe in the care of a well-functioning team; they can identify a key clinician who oversees their care; and they can access information and support from the team when they need it [V, B].

Supporting hope.

- Clinicians should recognise that supporting hope involves a collaborative process of communication, in which patients need to be able to trust in their clinicians' care [V, A].

- Clinicians need to be ready and able to recognise and respect hopes for the future that the patient wants to address and, conversely, cues that the patient wants to avoid thinking about the future [V, A].
- To support patients' hope, clinicians should not focus exclusively on the threatening aspects of the clinical situation, but also on what the clinicians can do to help [V, B].
- Step-by-step pairing of bad news with a positive message where appropriate, or with information about treatment or care, can also help patients maintain hope [V, B].

Interprofessional communication.

- Clinicians should ensure timely and accurate information exchange amongst relevant professionals [V, B].
- Clinicians should ensure that multidisciplinary team meetings are organised to allow the participation of relevant professionals [V, B].
- Members of the team need to be clear about their roles and responsibilities regarding patient care and communication about patients' needs [V, B].

Chronic cancer and survivorship.

- Clinicians should ensure that survivorship care plans include procedures for clear and timely communication within the clinical team and with patients [V, B].
- Clinicians should ensure that patients are educated about relevant issues such as surveillance or lifestyle changes [V, B].
- Teams should identify members responsible for monitoring and providing support, and for responding to patients' informational, emotional and practical needs [V, B].

Meetings with family or significant others.

- Family meetings should, where possible, be conducted by two staff members rather than a single clinician [V, B].
- Clinicians should aim to identify and address the needs that arise in individual family members because of the patient's disease and treatment and be alert to problems in family dynamics that damage the patient's or other family members' ability to adjust to the disease and to support the patient's care [V, B].
- Where family dynamics impair patients' adjustment to, or management of, the disease and treatment, or families' ability to support patients, families should have access to expert support and intervention [V, B].

TRAINING IN COMMUNICATION OF ONCOLOGY CLINICIANS

The Cochrane Database of Systematic Reviews reports that oncology clinicians who participated in training showed more empathy (high quality of evidence), used more open questions and less often provided 'medical facts only' (moderate quality of evidence, based on studies with simulated patients).[6] The evidence was low or very low quality regarding patient satisfaction with communication and patient anxiety. The review was unable to determine whether training effects persist, or which types of training are most effective. No support was found for effects of training on clinicians' burnout or patients' mental and physical health.

These limited positive findings must be considered cautiously because most outcome studies have not been rigorously designed (e.g. primary outcomes have rarely been defined in advance), and patient outcomes have only rarely been addressed.[11] Moreover, 'improved' communication was even associated with poorer mood in patients in one study.[91]

The position paper based on the third consensus meeting of European experts on training in communication of oncology clinicians addressed these and other criticisms of current training approaches.[7] In particular, the paper underlined the implausibility of conceptualising clinical communication solely as skills, the risk of standardising communication behaviour, a too narrow focus on technical (to the detriment of relational) aspects of communication, the proliferation of training programmes addressing very specific communication situations and the neglect of clinician-related and context-related aspects of communication. This third-position paper built on the first (addressing minimal quality requirements for training) and the second (providing detailed recommendations for specific aspects of training) but introduced a shift of perspective.

More specifically, this consensus meeting made the following recommendations. We grade them here at A (strongly recommended) because of their importance in equipping clinicians to make informed judgements about how to communicate in specific situations.

- Health care policy needs to promote a working climate that facilitates clinical communication and decreases the risk of depersonalised care [V, A].
- Training should aim to increase clinicians' awareness of factors related to their inner world (e.g. their emotions and experiences) and outer world (e.g. institutional constraints and society's dominant discourses) that shape clinical communication [V, A].
- Relational aspects of communication, such as interpersonal dynamics (e.g. authoritarian behaviour or prejudices regarding certain patient populations) and clinicians' defensive stances (e.g. anxious avoidance of patients' emotions) should be addressed in training [V, A].
- Training should enable trainees (i) to judiciously apply acquired communication competences by considering the patient's clinical and personal context, and (ii) to become aware of how they establish relationships with patients, significant others and team members and to reflect on themselves and on their communication behaviour [V, A].

RESEARCH ON COMMUNICATION IN CANCER CARE

Problematic aspects of quantitative research on clinical communication in the oncology setting include: (i) the often decontextualised approach (instances of communication can only be judged when taking into account the specific context and the communication process over time); (ii) the lack of clinical relevance of outcome measures; and (iii) the absence of patient outcomes in real-world settings.[8] Therefore, statistically generalisable research based on quantitative measurements of specific communication behaviours should be interpreted cautiously. Conversely, qualitative research can help to identify new ways of understanding communication, particularly when it explores not only the observed communication between patients and clinicians, but simultaneously how patients experience the communication and what clinicians were seeking to achieve by it.[20] Given that communication is not just a matter of achieving outcomes, but of implementing moral values, ethical reflection on communication practices is also an essential element of research in clinical communication.

Recommendations

- Qualitative research should be promoted, especially research attempting to link communication behaviour with the evaluation of clinicians' objectives and patients' experience in the communication process [V, A].
- Effects of clinicians' communication or communication training on patients in real-world settings should be a focus of future research on communication in cancer care [V, A].

METHODOLOGY

This CPG was developed in accordance with the ESMO standard operating procedures for CPGs development (https://www.esmo.org/Guidelines/ESMO-Guidelines-Methodology). The relevant literature has been selected by the expert authors.

Literature summarised to 2016 in the ASCO consensus guideline was consulted.[13] To identify literature published subsequently, papers were identified (published between 2016 and September 2022) which cited references included in the ASCO guideline, or that cited the guideline itself. Papers were retained that were published in English and that reported original research, guidelines and systematic reviews on clinicians' communication with patients and significant others in cancer care. Most retained papers addressed evaluation of communication skills training, followed by studies on disclosing prognostic information, compassion and empathy, BBN, costs related to communication and information provision. Cited references are those considered particularly helpful for clinicians who wish to deepen their understanding of issues mentioned in the present guideline. This guideline draws from literature and also from the clinical, educational and research experience of the authors, who provide expertise from oncology, palliative care, psychology, psychiatry, psychosomatics, internal medicine, psychotherapy and social sciences. Guideline text and recommendations were agreed by consensus among the members of the author group.

Levels of evidence and grades of recommendation have been applied using the system shown in Supplementary Table S1, available at https://doi.org/10.1016/j.esmoop.2024.103496.[92] Statements without grading were considered justified standard clinical practice by the authors. For future updates to this CPG, including eUpdates and Living Guidelines, please see the ESMO Guidelines website: https://www.esmo.org/guidelines/guidelines-by-topic/esmo-clinical-practice-guidelines-supportive-and-palliative-care/communication-and-support-of-patients-and-caregivers-in-chronic-cancer.

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