

# Experiences of Patients and Families Living with Cancer: Communication, Decision-Making, and Support

*An Integrative Review of Patient- and Family-Centered Oncology Care*

**Dr. Khalid Hameed**

Consultant Medical Oncologist

MBBS, MRCP, MRCPI, MSc, Advanced Master's in Comprehensive Medical Oncology

Queen Alexandra Portsmouth Hospital, University NHS Trust

Cosham, Portsmouth PO6 3LY, United Kingdom

St Richard's University Hospital

Spitalfield Lane, Chichester PO19 6SE, United Kingdom

Email: [KSHAMEED@GMAIL.COM](mailto:KSHAMEED@GMAIL.COM)

ORCID: 0009-0009-7101-2029

## Abstract:

**Background:** Cancer affects patients and families as a shared medical, emotional, and practical experience. This review examines how communication, decision-making, and caregiver support promote understanding, coping with uncertainty, and the enactment of care in the context of patients and their families.

**Methods:** Targeted PubMed/MEDLINE searches and citation chaining were used to perform an integrative narrative review. Studies from 2019-2025 were selected, and influential earlier studies were included when clinically relevant. Studies were organized into three domains: communication, decision-making, and support, and were compared thematically with the aim of identifying common mechanisms and implications for practice.

**Results:** The evidence yielded four recurring outcomes: shared understanding, emotional responsiveness, role clarity, and continuity. Patients and families valued clear, honest communication that was emotionally attentive and appropriately paced. Shared decision-making was most effective when options were clear, goals were elicited, family roles were discussed, and the patient's voice was preserved in discussions of family involvement. Information, symptoms, logistics, and treatment implementation were typically managed by caregivers; however, their preparedness and burden were not consistently assessed. Structured conversations, patient coaching, caregiver interventions, and early palliative care improved selected outcomes, although effects were not consistent across contexts or intervention designs.

**Conclusion:** The coordination of communication, decision-making, and caregiver support should form a unified clinical process. Reassessment of understanding and information needs, decisional roles, family

involvement, health literacy, caregiver capacity, and psychosocial needs can help align care with patient goals while reducing unnecessary uncertainty and caregiver burden.

**Keywords:** Cancer; oncology; family caregivers; communication; shared decision-making; patient-centered care; supportive care; palliative care.

## 1. Introduction

Cancer affects more than just the patient's health. Patients and family members must decipher unfamiliar medical jargon from diagnosis through treatment, weigh the benefits and burdens of treatment, rearrange roles at work and home, manage symptoms, and deal with uncertainty about the future. These tasks frequently occur when a person is afraid, fatigued, in pain, and cognitively overloaded. Communication, decision-making, and support are therefore integral to safe oncology care because they influence the extent to which patients and families understand the care plan, trust the oncology team, participate in decision-making as they wish, and implement care outside the hospital. These processes are associated with satisfaction, emotional adjustment, adherence, readiness, and the extent to which treatment is congruent with patient values (Bernacki & Block, 2014; Kehl et al., 2015; Shickh et al., 2023).

Today's cancer care is also relational and dispersed across settings. Patients can transition from outpatient clinics through infusion units, surgical and radiation services, emergency departments, home care, survivorship programs, and palliative care. Family members are often with the patient and can aid recall, ask questions of healthcare providers, arrange medications and transportation, monitor symptoms, and translate provider instructions into home care. During terminal illness, family members can also help patients reflect on whether continued treatment is consistent with their wishes and goals, or act as surrogate decision-makers when patients are no longer able to decide for themselves. Results from a national survey analysis showed that family caregivers play a variety of roles in treatment decision support, but they are not always sure how they can be involved, how to access complex information, or how to communicate with oncology professionals (Dionne-Odom et al., 2023).

These interactions can either make things worse or better. Westendorp et al. (2023) reported that patient and caregiver experiences of poor communication included not being listened to, not being treated with empathy, unclear and/or contradictory information, poorly timed information, avoidance of difficult topics, and low levels of involvement. Caregivers, however, appreciate attentiveness, sincerity, availability, and responsiveness to the realities of family life (Washington et al., 2019). The distinction is between the delivery of information and relational communication. A technically correct explanation can still be ineffective if it is not understandable, emotionally responsive, and connected to what the patient and family need to do next.

Another layer of complexity in cancer treatment decision-making is that there are many preference-sensitive choices. Options may provide similar disease control but differ in toxicity, efficacy, convenience, impact on fertility, long-term risks, or risk of hospitalization. Shared decision-making (SDM) is designed to bring together evidence, patient values and goals, and the patient's circumstances. It is not easy to implement. Patients differ in their preferences for decisional control, families have varying roles and expectations, and clinicians must discuss choices under uncertainty. Clinician

assumptions, lack of invitation to participate, limited trust, insufficient understandable information or decision support, time pressure, information overload, and poor communication are consistently cited as barriers (Covvey et al., 2019; Zheng et al., 2024).

Support needs do not end after a consultation. Anxiety, sleep disturbances, role strain, financial and work strain, social isolation, and physical exhaustion are reported by caregivers, and these stressors may fluctuate with disease and functional status (Northouse et al., 2012; Stenberg et al., 2010). Recent reviews indicate that support is more helpful when it addresses practical care tasks and emotional needs through education, psychological support, stress-management and communication support, and interventions targeting the patient-caregiver dyad (Ahn et al., 2020; Kajiwarara et al., 2024). This is important because a treatment program that is medically sound and appropriate may still be impractical or impossible to implement without sufficient information, skills, time, or emotional resources from the family.

The aim of this integrative review is to examine patient and family experiences of cancer treatment in three interrelated domains: communication with healthcare providers, involvement in treatment and goals-of-care discussions, and formal and informal support. The review aims to summarize common experiences reported in the literature, identify mechanisms that enhance or impede care, and make practical recommendations for oncology teams. The review focuses on the patient-family unit as a dynamic relationship. Needs range from highly individual decision-making to substantial family involvement, and either may change as treatment burden increases, disease evolves, or capacity diminishes. Hence, personalization and repeated reassessment are integral to patient- and family-centered care (PFC).

## **2. Methods**

### **2.1 Review Design and Rationale**

An integrative narrative review design was used because the research question spans heterogeneous evidence that cannot be meaningfully reduced to a single pooled effect. Qualitative studies of lived experience, survey studies, randomized communication interventions, and caregiver support studies are represented in the relevant literature, as are systematic or scoping reviews of SDM and palliative communication. The aim was not to estimate the effectiveness of interventions through meta-analysis but to identify common ground, clinically relevant differences, and recurring mechanisms from the perspectives of patients, caregivers, and healthcare professionals.

### **2.2 Literature Search Strategy**

A systematic search of PubMed/MEDLINE, together with backward and forward citation searches of selected reviews and primary studies, was conducted. Search concepts included cancer and oncology, communication, family caregivers, patient experience, shared decision-making, treatment decisions, serious illness conversations, caregiver burden, psychosocial support, palliative care, and health literacy. The search focused on literature published from 2019 to 2025 to reflect current oncology practice. Earlier research was included when it identified a framework or evidence that remains clinically relevant, such as the SPIKES protocol, early palliative-care trial literature, and foundational literature on caregiver burden.

### 2.3 Eligibility Criteria and Source Selection

Eligible sources addressed communication, decision-making, supportive care, and/or caregiver experiences among adults with cancer and their family or informal caregivers. Systematic reviews, meta-syntheses, scoping reviews, randomized or cluster-randomized trials, national survey analyses, and qualitative studies were considered when they specifically included patient- or family-centered outcomes. Studies focused primarily on antitumor efficacy were not emphasized unless they also measured communication, decision-making, caregiver, or supportive-care outcomes. Because this is an integrative narrative review rather than a systematic review, it was not intended to identify all eligible studies, and no formal risk-of-bias assessment or meta-analysis was conducted. Conclusions are therefore presented as thematic and interpretive findings rather than comprehensive effect estimates.

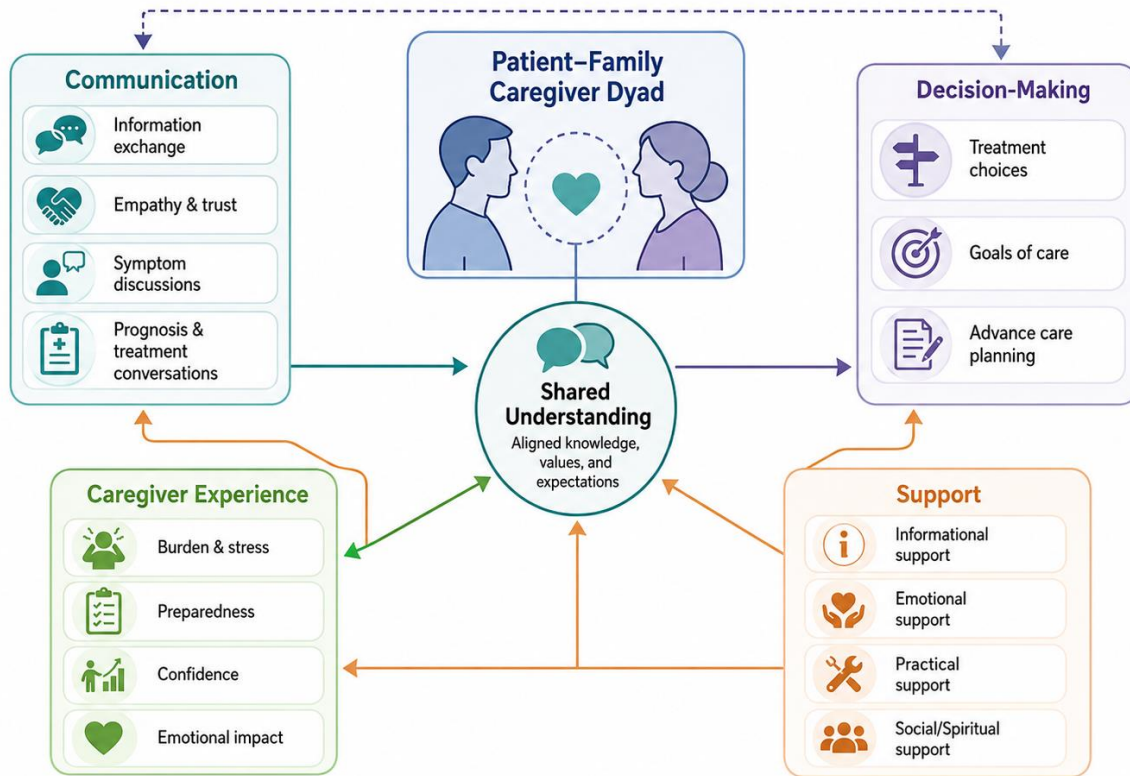
### 2.4 Data Synthesis and Analysis

Evidence was synthesized in a series of steps. Findings were first categorized according to the three prespecified domains of communication, decision-making, and support. Second, cross-cutting mechanisms were identified, including emotional recognition, trust, health literacy, clarity of family roles, uncertainty, continuity, preparedness, and timing. Third, descriptive and qualitative evidence was used to compare intervention findings and assess whether proposed interventions addressed problems reported by patients and caregivers. The synthesis focused on findings that were consistent across two or more sources while acknowledging differences in preferences, settings, cancer stages, and intervention outcomes.

## 3. Results

Communication, decision-making, and support were not services delivered in isolation; rather, they were interdependent across the literature. Effective communication improved understanding and trust, leading to greater involvement in decision-making. Explicit connections to goals reduced uncertainty and enabled families to plan for the type of care needed. Caregiver support, in turn, was related to the safety of agreed plans at home. Failure in one element often affected the others: unclear information led to decisional conflict, unrecognized emotion reduced information processing, poorly defined family roles led to tension, and poor caregiver preparation increased burden and the risk of fragmented care. These relationships are summarized in Figure 1.

Four cross-cutting mechanisms were particularly consistent in the included evidence. Shared understanding involved more than factual disclosure; patients and caregivers needed prioritized, understandable, and connected information. Second, emotional responsiveness affected how difficult information was processed. Third, role clarity was important in triadic interactions because the patient, caregiver, and clinician might have different expectations regarding who should be informed and who should make decisions. Fourth, continuity minimized the stress of having to repeat the illness narrative in different settings. These mechanisms structure the following domain-specific findings.



**Figure 1. Dyadic model linking communication, shared understanding, decision-making, caregiver experience, and support in cancer care**

The major recurring domains identified across patient and family experiences are presented in Table 1.

**Table 1. Recurring domains in patient and family experiences of cancer care**

| Domain        | Patient experience                                                                               | Family/caregiver experience                                                                                    | Representative evidence                                     |
|---------------|--------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|
| Communication | Clear, honest, paced information; empathy; consistent messages; access to a responsive clinician | Recognition as a legitimate care partner; permission to ask questions; information required for safe home care | Li et al., 2020; Westendorp et al., 2023; Wang et al., 2024 |

|                  |                                                                                                                                 |                                                                                                                         |                                                                      |
|------------------|---------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------|
| Decision-making  | Awareness that a choice exists; understandable comparison of options; elicitation of goals; preferred decisional role respected | Role clarity; support without displacing the patient; inclusion when desired and permitted by the patient               | Kehl et al., 2015; Dionne-Odom et al., 2023; Shickh et al., 2023     |
| Support          | Symptom, psychological, practical, spiritual, financial, rehabilitation, and navigation support tailored to changing needs      | Preparation for caregiving tasks; education; respite; emotional care; coping and stress-management resources            | Ahn et al., 2020; Northouse et al., 2012; Kajiwarra et al., 2024     |
| Advanced illness | Prognostic communication; goals and trade-offs; continuity; anticipatory planning; repeated review of preferences               | Preparation for deterioration; shared understanding of goals; role clarification; support before and during bereavement | Bernacki & Block, 2014; Rabben et al., 2024; Laryionava et al., 2021 |

### 3.1 Communication Experiences: Information, Emotion, and Trust

Consistent patient and family feedback indicated that effective communication was clear, honest, empathetic, individualized, and appropriately paced. Li et al. (2020) found that communication needs differed between patients and caregivers in terms of who initiates communication, what is discussed, when discussions occur, and how information is delivered. They also found that communication needs change over the course of illness. At diagnosis, patients may need information about what is known and what may occur in the future. During treatment, the focus may shift to side effects, symptom monitoring, logistics, and understanding treatment response. During survivorship, concerns may center on recurrence, whereas progression may increase the importance of prognosis, goals, and transitions in care. Communication needs should therefore not be assumed to remain constant after the initial consultation. Informational accuracy alone was not paramount; emotional responsiveness was also essential. During stressful consultations, patients may be unable to recall all the statistics, but they often remember whether clinicians allowed silence, remained patient with questions, and stayed present when delivering bad news. The SPIKES framework formalized several of these behaviors and includes the following components: setting, the patient's perception and information needs, knowledge delivery, response to

emotion, and a clear plan for next steps (Baile et al., 2000). Such frameworks are not intended to be scripts. Instead, they help clinicians avoid common errors, such as providing too much information too quickly, moving into technical details while emotion dominates the conversation, or ending a difficult conversation without summarizing what will happen next.

The literature also helps explain how communication can cause harm. Westendorp et al. (2023) identified rushed interactions, failure to listen, minimization of concerns, unclear or contradictory language, avoidance of sensitive topics, and lack of compassion from clinicians. Harm can occur even without an obvious display of disrespect. Reassurance can lead to misinterpretation if it is not paired with realistic preparation; an overly technical approach can obscure the meaning of a treatment plan; and contradictory messages from different clinicians can reduce trust. The need is therefore not simply for more information, but for prioritized information that makes clear what the patient and family should understand, decide, monitor, and act on next.

Communication between caregivers and healthcare professionals is also important. Wang et al. (2024) categorized caregiver-professional communication as relationship building, information sharing, acknowledgment of caregiver emotions, support for decision-making, and help with care management. Patient autonomy and confidentiality must be considered when balancing these needs. One strategy is to discuss early with the patient who should be involved, what information may be shared, and what role each person should play. Explicit negotiation can prevent two common problems: a caregiver being excluded from information needed for safe home care, or a relative taking over the consultation and diminishing the patient's voice.

Communication within the family can create additional work. Caregivers can become information brokers, sharing information about diagnosis, prognosis, and treatment with other family members while also attempting to shield the person with cancer from further questions or distress. According to Wittenberg et al. (2017), communication responsibilities can contribute to caregiver burden and affect quality of life. In some patient-caregiver dyads, concerns are also deferred through a process known as protective buffering. This may help maintain emotional balance in the short term but can also delay discussion of support needs and future planning. Clinicians can help by normalizing different coping styles and asking whether the patient and caregiver can talk about changes, concerns, and real-life needs. Health literacy and health numeracy influence how oncology information is interpreted and acted upon. Probabilities of recurrence, absolute versus relative treatment benefit, genomic biomarkers, treatment schedules, and competing risks may need to be explained to patients and/or caregivers. Although caregivers are often expected to understand information and help implement care, caregiver health literacy remains largely under-researched, as reported by Moore et al. (2021). Using simple language, teach-back, written summaries, visual representations of risk, and trusted information sources can reduce unnecessary misunderstandings. This is especially important when patients or caregivers are tired, anxious, unfamiliar with the healthcare system, or managing multiple treatment plans.

Honesty and sensitivity are especially important in end-of-life situations. Families differ in when and how much prognostic information they want, and inaccurate or poorly timed communication can leave them unable to anticipate deterioration, leading to crisis communication and decisions. Bernacki and Block (2014) describe practices that include discussing prognosis, clarifying patient preferences and

goals, exploring fears, considering trade-offs, and determining how family members will be involved. The Serious Illness Care Program (SICP) was designed to facilitate these conversations earlier and in a more structured manner; in a cluster-randomized trial, SICP was associated with lower psychological distress and anxiety in some, but not all, analyses (Bernacki et al., 2019). Good prognostic communication does not mean taking away hope. It can redirect hope toward attainable goals, such as symptom control, time at home, meaningful activities, preserving function, and maintaining relationships.

### **3.2 Decision-Making Experiences: Autonomy, Family Roles, and Uncertainty**

Shared decision-making can be viewed as a clinical process in which the patient and clinician acknowledge that a choice exists, consider the options, discuss benefits and burdens, consider the patient's values and circumstances, and agree on a plan that is both clinically appropriate and personally acceptable. This is particularly relevant in oncology, where uncertainty is high and the effects of treatment on functioning, symptoms, time, fertility, work, finances, and family life may be as important as survival. SDM is not merely a technique used during a single consultation. Shickh et al. (2023) suggest that SDM can be considered a form of ongoing care. The aim is not only to document that options were discussed but to develop a care plan that the patient can accept medically, practically, and emotionally.

Preferences for decisional control are heterogeneous. Some patients prefer to make the final decision after the physician has made a recommendation, some prefer to share the decision, and others prefer the clinician to make a recommendation or decision after understanding their values. The ethical aim is not to give the patient maximum control in every scenario, but to support participation that matches the patient's preferred role. Kehl et al. (2015) examined associations between actual and preferred decision roles and patient-reported quality of care and communication. Clinicians should not use age, culture, education, or self-confidence as proxies for how decisions should be made.

When family members are involved, the clinician-patient relationship becomes triadic. Family members can provide information about the patient's roles, past statements, goals, and home management. They may help compare options and remember information, but their preferences may differ from the patient's. Dijkman et al. (2022) identified patient, caregiver, family, clinician, and cultural factors that influence how families are engaged in treatment decisions for older adults with cancer. Family-centered care does not therefore mean maximizing family involvement. It involves negotiating an appropriate role while maintaining the patient's autonomy, preferences, and confidentiality.

Dionne-Odom et al. (2023) showed that caregivers contribute to decisions by collecting information, helping patients ask questions, attending consultations, weighing options, and supporting implementation after decisions are made. These activities become more difficult when information is incomplete, roles are ambiguous, or family conflict is present. A basic triadic structure can make implicit expectations explicit at key decision points: What decision role does the patient prefer? What roles should the patient and family member undertake? What practical supports are needed to make the selected plan feasible? Explicit answers can help prevent misunderstandings and reduce the risk that family support becomes family control.

Barriers to SDM occur at the patient, clinician, and system levels. Covvey et al. (2019) identified uncertainty, concerns about adverse effects, communication problems, and structural barriers, while Zheng et al. (2024) showed that knowledge, emotions, clinician communication, and context influence decision behavior in breast cancer surgery. Although time pressure is often cited, low SDM can also occur when a recommendation is presented as the only feasible choice, when patients are reluctant to ask questions because they do not want to be a burden, or when information is too complex to allow a meaningful comparison. Decision aids can help with preparation and structure, but they are best used to support conversation rather than replace it.

As disease progresses, uncertainty, emotional pressure, and family involvement increase, as may the number of potentially feasible options. Rabben et al. (2024) identify progression, lack of equipoise, existential concerns, and involvement of multiple professionals and relatives as sources of complexity in palliative cancer care. Choices regarding additional cancer therapies, hospitalization, artificial nutrition, resuscitation, or hospice are seldom made on purely technical grounds. They can also carry meanings related to hope, loyalty, duty, or fear of 'giving up.' Close family members have also been shown to be important participants in decisions near the end of life (Laryionava et al., 2021). It is important to address both the clinical trade-offs and the moral and emotional implications that patients and families bring to these decisions.

The same conflicts can occur earlier in the disease course when treatment de-escalation is discussed. Trust in clinicians, perceived risk, expectations about quality of life, and the need for timely and understandable information were identified as factors influencing patient and caregiver attitudes toward reduced treatment intensity (Hamilton et al., 2025). This finding is applicable beyond formal de-escalation trials. For some patients, more treatment may seem to mean more care unless they understand that treatment which adds unnecessary toxicity, burden, or inconvenience is not necessarily better care. Framing is important: a less intensive plan should be presented as an active, evidence-informed choice rather than as therapeutic withdrawal.

There is considerable variation in interventions designed to improve decision quality. Structured interventions in advanced cancer consultations have shown positive effects on perceptions of SDM, but the number and nature of studies make it difficult to determine which approaches are most effective (Punnett et al., 2024). Decision support should be embedded into routine workflow by preparing questions before the visit, making the choice explicit, comparing benefits and burdens in understandable terms, eliciting values, using teach-back to check comprehension, and documenting the priorities that should guide the choice. This approach makes the decision-making process more transparent and less dependent on an individual clinician's communication style.

### **3.3 Support Experiences: Caregiver Burden, Dyadic Care, and Palliative Support**

Patients and families may require assistance with symptom management, psychological support, spiritual concerns, rehabilitation, financial concerns, transportation, nutrition, fertility, employment, peer support, and navigation of services. Caregivers have many of the same emotional support needs but also need preparation for the practical aspects of caring for another person. Fatigue, anxiety, depressive symptoms, impaired social functioning, and financial strain are often reported in the caregiver literature

and can worsen as patient functioning deteriorates (Northouse et al., 2012; Stenberg et al., 2010). The breadth of these needs argues against treating support as a one-time referral. Needs should be reviewed repeatedly because the type and level of support required may change substantially during treatment, progression, and transitions in care.

A significant problem is that caregivers are often viewed as part of the healthcare workforce rather than as individuals with their own limits and support needs. Family members may be expected to administer medications, monitor symptoms, arrange appointments, help with mobility and personal care, identify emergencies, and coordinate services without training. This unrecognized work at home can lead to underestimation of the caregiver workload. Caregiver assessment should therefore identify who is providing care, what is expected of them, how confident they feel performing these tasks, whether other responsibilities conflict with caregiving, and what signs would make the arrangement unsafe or unsustainable.

Caregiver support interventions may be more effective when directed at identified skills and needs. Ahn et al. (2020) reviewed psychosocial and educational interventions for family caregivers of individuals with advanced cancer at home and found that studies reported outcomes involving distress, caregiver burden, quality of life, self-efficacy, and caregiving competence, although intervention content and effects varied. Jadalla et al. (2020) also found evidence for interventions addressing caregiver stress but reported variation in how these interventions were delivered. Kajiwarra et al. (2024) categorized nursing support into psychological, educational, telephone- or technology-based, stress-reduction, mindfulness-related, and dyadic interventions. Collectively, the evidence supports proactive preparation before a caregiver crisis rather than referral only when burden is high.

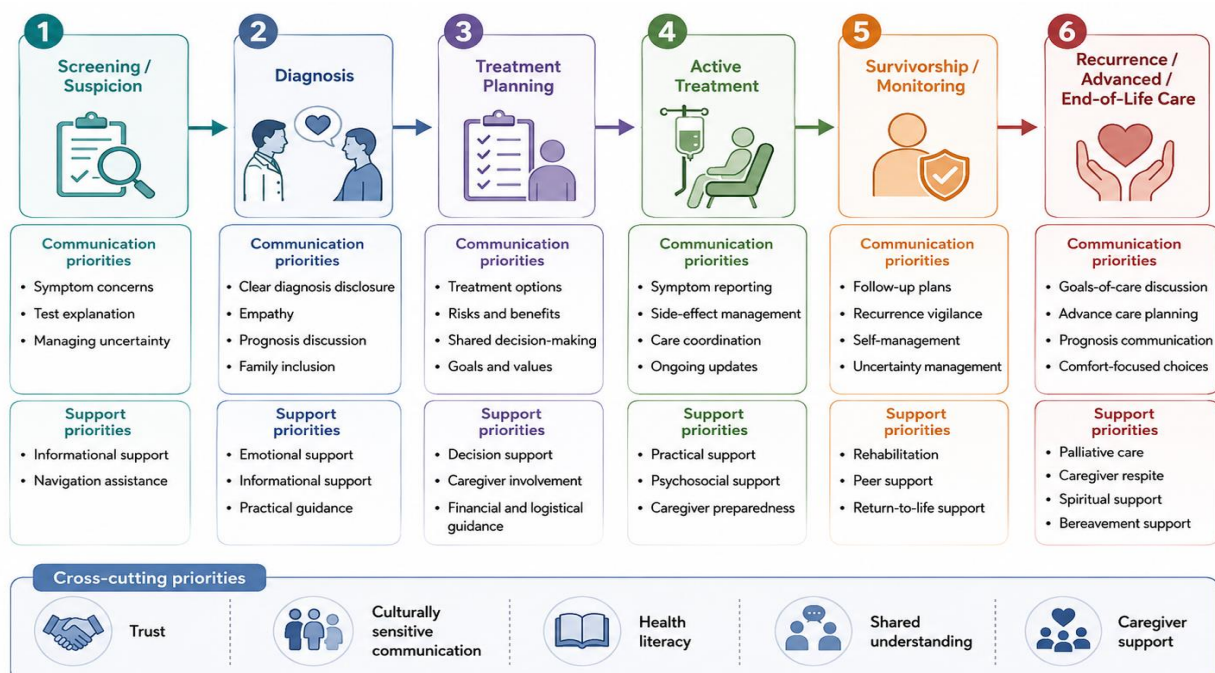
Family-centered care is also important because cancer can change how family members communicate and how roles are distributed within the family. Coyne et al. (2020) conceptualize cancer as a 'family disease' because its effects can extend throughout the family system, and communication within the family can influence adaptation. During the illness, patient-caregiver dyads may become very close, avoid confronting difficult issues, disagree about treatment, or even reverse roles. Support should therefore be adaptable. Some couples benefit from joint instruction, communication coaching, and problem-solving; others require individual instruction and coaching so that concerns can be expressed without fear of hurting the other person.

Palliative care offers a model of integrated support because it includes symptom management, communication, coping support, attention to family needs, future planning, and disease-specific therapy. In a landmark trial (Temel et al., 2010), early palliative care for patients with metastatic non-small-cell lung cancer (NSCLC) improved quality of life and mood and was associated with less aggressive care at the end of life. More recent studies of palliative communication also highlight the importance of clear, empathetic communication, tailoring information to the individual, and considering what the patient and family member want and need (Engel et al., 2023). Palliative care therefore extends beyond the last few days of life. Earlier engagement can provide repeated opportunities for symptom management, values clarification, caregiver support, and prevention of crisis-driven decisions.

Equity and feasibility should be considered when planning support. Appropriate recommendations may be difficult to follow because of limited health literacy, language barriers, rural residence, insecure

employment, low income, disability, or poor social support. Cultural norms may influence who receives information first, how information is shared, and whether family agreement is expected for major decisions. There is no single 'right' way to disclose information or involve families. A better approach is to ask rather than assume: what the patient wants to know, who the patient wants present, how information should be conveyed, and how important family consensus is. This approach considers cultural context without stereotyping the patient.

Continuity is also a form of support. Patients and families often have to recount the illness history repeatedly to new clinicians, may receive conflicting information, or may be unsure whom to contact if symptoms change. A brief written care summary, a designated contact person, communication across the team, and an after-hours plan can reduce the cognitive and logistical burden. Transitions from hospital to home, between periods of active treatment, and from disease-directed treatment to comfort-focused care are particularly important for continuity. As shown in Figure 2, communication and support priorities shift throughout the cancer experience.



**Figure 2. Communication and support priorities across the cancer trajectory**

All of the findings point toward the need for high-quality oncology care to consistently address three related questions: What does the patient understand, and what does the patient want to know? How will decisions be made, including the role of family members? How can the patient-family system be supported to implement the plan safely? Table 1 presents the key experiential domains, and Table 2 translates these domains into actions that can be integrated into a typical clinical encounter.

Evidence-informed clinical actions supporting patient- and family-centered oncology communication are summarized in Table 2.

**Table 2. Evidence-informed actions for patient- and family-centered oncology communication**

| Clinical moment             | Recommended action                                                                                                                                                                                           |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Before a major consultation | Ask who the patient wants present; assess current understanding; identify preferred information depth, decision role, and any communication barriers.                                                        |
| When explaining options     | State clearly that a choice exists; use plain language and absolute risks when possible; compare benefits, burdens, and practical consequences; provide a written summary.                                   |
| When emotion appears        | Pause; acknowledge the emotion; allow silence; explore the concern briefly; then check readiness before adding technical information.                                                                        |
| When family is involved     | Confirm patient permission; define the caregiver role; invite relevant observations; return the final focus to the patient's goals and preferences.                                                          |
| At treatment transitions    | Explain what is changing and why; identify a contact person; review red flags, symptom plans, medicines, and responsibilities at home; confirm understanding with teach-back.                                |
| With advanced disease       | Discuss prognosis and goals early and iteratively; explore fears, acceptable trade-offs, preferred family involvement, and priorities for function, place of care, and symptom control.                      |
| For caregiver support       | Assess preparedness, burden, health literacy, and competing responsibilities; teach specific tasks; provide nursing, psychosocial, social-work, rehabilitation, and palliative-care referrals before crisis. |

Selected intervention evidence supporting communication, decision-making, and caregiver support is presented in Table 3.

**Table 3. Selected intervention evidence relevant to communication, decision-making, and caregiver support**

| Study                 | Design                          | Intervention focus                                           | Key contribution and interpretive caveat                                                                                                                                                                     |
|-----------------------|---------------------------------|--------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Epstein et al., 2017  | VOICE randomized clinical trial | Advanced cancer communication training plus patient coaching | Improved patient-centered communication, but secondary clinical outcomes were not consistently changed, indicating that better communication does not automatically translate into every downstream outcome. |
| Bernacki et al., 2019 | Cluster-randomized trial        | Serious Illness Care Program                                 | Supported earlier and more structured goals-of-care conversations and lower anxiety in some analyses without increasing distress; effects depended on the outcome assessed.                                  |
| Ahn et al., 2020      | Systematic review               | Psychosocial and educational caregiver interventions         | Many studies reported lower distress or burden, or better quality of life, self-efficacy, or competence, but substantial heterogeneity limits conclusions about a single optimal intervention.               |

|                        |                   |                                                  |                                                                                                                                                                                                     |
|------------------------|-------------------|--------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Punnett et al., 2024   | Systematic review | Decision-making interventions in advanced cancer | Structured approaches can improve perceived shared decision-making, although the evidence base remains heterogeneous and does not establish which components are essential.                         |
| Kajiwarra et al., 2024 | Scoping review    | Nursing support for caregiver burden             | Mapped psychological, educational, telephone or ICT, stress-reduction, mindfulness, and dyadic components, supporting a flexible package of support rather than a single standardized intervention. |

## 4. Discussion

### 4.1 Integrated Interpretation and Clinical Meaning

The central finding of this review is that communication, decision-making, and support function as one clinical system from the patient and family's perspective. Typically, these roles are divided among professionals: physicians lead treatment, nurses provide education, social workers assist with practical matters, and palliative care clinicians become involved when needed. Patients and families, however, experience the cumulative effects of this fragmentation. Unclear information can increase anxiety; anxiety can hinder information processing; poor understanding can reduce participation in decisions; and an impractical decision can shift unrecognized work onto the caregiver. Fragmentation is therefore not merely an organizational issue. It can affect the understanding, selection, and implementation of a treatment plan.

A second finding is that personalization is more appropriate than any entrenched notion of 'maximal disclosure,' 'maximal autonomy,' or 'maximal family involvement.' Patients vary in how much information they want, how quickly they want it, how much they wish to share, with whom they wish to share it, and which people are available to support them. Preferences may also shift as disease and treatment evolve, fatigue increases, or family circumstances change. Repeated preference elicitation may therefore be more clinically useful than a single assessment. Teams can reassess information needs,

decision-making roles, and family engagement before and after major transitions and confirm whether the process remains aligned with the patient's wishes.

Empathy is a skill rather than a personal characteristic. Patients and caregivers view inattention, lack of emotional responsiveness, and avoidance of emotion as negative communication behaviors (Westendorp et al., 2023). Structured approaches translate empathy into practice through attention to setting, understanding, preferences, clear language, recognition and response to emotion, summary, and planning (Baile et al., 2000; Bernacki et al., 2019). Training should therefore focus on behaviors that can be practiced, observed, and improved rather than on memorizing a list of 'scripts' that may result in mechanical and ineffective communication.

Caregiver assessment should be routine rather than optional. Family members are a key component of modern outpatient oncology, but their capacity is not routinely assessed alongside performance status, toxicity, or symptom burden. A caregiver who is overwhelmed, confused, in poor health, or has limited financial resources can become a weak link in an otherwise sound treatment plan. Evidence from caregiver interventions supports education, coping support, stress management, task-specific training, and accessible follow-up (Ahn et al., 2020; Jadalla et al., 2020; Kajiwarra et al., 2024). A basic clinical response includes identifying the primary caregiver, defining expected roles, assessing confidence and burden, and arranging referrals before the situation becomes unsafe.

Deliberation, rather than independent treatment choice, should be the basis for judging the quality of SDM. It may be entirely appropriate for a patient who understands the options and has discussed their goals to ask the clinician for a recommendation. Conversely, giving a patient multiple options without explaining the implications of each choice can constitute abandonment in the guise of choice. Awareness of options, understandable information, elicitation of values, and alignment with the patient's preferred role are consistently identified in oncology SDM research (Covvey et al., 2019; Kehl et al., 2015; Shickh et al., 2023). Explicit role clarity for caregivers should be included in triadic consultations using the same standard.

These principles are especially relevant in advanced cancer and end-of-life care. If prognosis is not well explained, families may be unprepared for deterioration, which can lead to crisis decisions. Early serious-illness and palliative-care discussions allow preparation, goal clarification, and plan adjustment as the clinical situation evolves (Bernacki & Block, 2014; Temel et al., 2010). Hope does not need to be dismissed. Clinicians can communicate prognosis honestly while helping patients set achievable goals that remain meaningful, such as symptom relief, time with family, functional priorities, or the preferred place of care.

Digital tools can supplement relational care but should not replace it. Patients who cannot attend every appointment may gain additional access to information through patient portals, telehealth, electronic education, and decision-support tools. Digital communication may also create disparities when access to technology, language support, health literacy, confidence with digital tools, or accessibility for people with disabilities is limited. The same principles discussed in this review still apply: information should be comprehensible, responsive to users' needs, and linked to a human channel for questions and emotional support. Accessibility and equity should therefore be considered alongside technical availability when digital tools are implemented.

#### **4.2 Strengths and Limitations**

This review has several limitations. It used targeted searches and citation chaining rather than a systematic search of multiple databases; therefore, relevant studies may have been missed, and the evidence base should not be considered exhaustive. No formal risk-of-bias assessment was conducted, limiting the ability to weight individual studies according to methodological quality. The literature includes varied cancer types, disease stages, healthcare systems, cultures, and intervention designs, so the findings should not be assumed to apply to all patients or caregivers. Evidence comes largely from high-income settings that may differ in access, staffing, family roles, and financial protection, which may limit transferability. Caregiver samples also disproportionately include spouses and women, and intervention studies vary in outcomes and follow-up duration. These limitations mean that the review should support implementation and interpretation rather than define a single communication protocol.

#### **4.3 Research and Implementation Priorities**

Future studies need to move beyond describing patient- and family-centered practice to testing its reliable implementation in routine oncology. Priorities include more diverse patient-caregiver dyads, longitudinal studies that follow communication and support needs over time, and pragmatic trials within current clinical workflows. Outcomes should extend beyond satisfaction to include decisional conflict, goal-concordant care, caregiver preparedness, family quality of life, symptom crises, treatment burden, and equity. Implementation studies should also determine which tasks can be standardized, which require individual tailoring, who should conduct caregiver assessments, and how communication and support can be documented without creating an unacceptable workload. Family roles, available services, financial stressors, and the quality of palliative or psychosocial care may differ substantially from the settings where most research has been conducted, particularly in low- and middle-income communities.

#### **5. Conclusion**

Living with cancer is a shared experience even when the patient remains the central decision-maker. Patients and their families must build understanding, cope with emotions, make important decisions, and carry out treatment plans repeatedly over time. The implications for safe and effective care are clear: communication between clinicians and patients should be clear and empathetic, choices and trade-offs should be explicit, patient goals should be elicited, family involvement should be negotiated, and caregivers should be viewed as people with their own capacities and needs.

Assessments of understanding, information preferences, decisional roles, health literacy, caregiver capacity, and psychosocial needs therefore need to be repeated throughout the illness trajectory to support high-quality oncology care. Structured communication tools, serious-illness conversations, SDM practices, caregiver education, and early palliative care should be considered parts of the same care process. The practical goal is to build shared understanding, clarify roles, and ensure that the selected plan is clinically appropriate and feasible for the patient-family system. Incorporating these practices into routine oncology workflow provides a more direct pathway between patient-centered principles and consistent clinical care.

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