



Role of the Nurse in Patient Education and Engagement and Its Importance in Advanced Breast Cancer

Catherine Oakley^{a,*,†}, Emma Ream^{b,†}

^a Chemotherapy Nurse Consultant, Guy's and St Thomas' NHS Foundation Trust, Guy's Hospital, London, UK

^b Professor of Supportive Cancer Care and Director of Research, School of Health Sciences, University of Surrey, Guildford, UK

ARTICLE INFO

Key Words:

Cancer
Carers
Patient-centered communication
Patient engagement
Relational care

ABSTRACT

Objectives: To show how people with cancer, including those with advanced breast cancer, engage with information and self-management and how cancer nurses can support patients to manage important aspects of care. Epstein and Street's patient-centered communication in cancer care (PCC) model provides a useful framework. The model incorporates six domains representing core mediating functions of patient-centered communication (Fostering healing relationships, Exchanging information, Responding to emotions, Managing uncertainty, Making decisions, and Enabling self-management) and additional moderating factors for PCC and health outcomes.

Data Sources: Data sources include peer-reviewed articles sourced from electronic databases.

Conclusion: Common complex interrelated reasons for poor engagement include fear, denial, fatalism, bereavement, advanced disease, and poor clinician–patient relationships. This can have serious implications for physical and emotional outcomes. Facilitators include open, trusting relationships between patients and nurses, timing of information, focusing on patients' agendas, and understanding emotional concerns, beliefs, and motivations. Supporting patients and carers to work together, through evidence-based interventions and tailoring approaches, for example to older people, are important.

Implications for Nursing Practice: Patient information and engagement are important aspects of cancer nursing. Interventions are largely based on behavior change theory, but new translational research is needed to demonstrate effectiveness. Nurses need education on how to develop skills to effectively manage this complex process to effectively engage and educate patients.

© 2023 Elsevier Inc. All rights reserved.

Introduction

Breast cancer increases in incidence with age, with incidence rates peaking at ages 65–69 years,¹ meaning many people living with the disease are also living with age-associated challenges. Challenges include other chronic conditions, vision or hearing impairments, and/or age-related cognitive decline.² These can impede patient engagement and communication. At the same time, treatments for cancer are developing apace; contemporary treatment often entails complex and multiple lines of therapy, adding complexity to self-care demands that patients face.

Self-care during and following treatment includes patients seeking help in a timely fashion for new or concerning symptoms and side effects. Late presentation is of particular concern as this can affect morbidity and mortality. Factors including fear, denial, poor

motivation, miscalculation of symptom severity, self-medication, advanced disease, bereavement, fatalism, carer exclusion, and poor clinician relationships are established contributors.^{3–6} Cancer nurses are crucial in supporting patients to self-manage physical and psychological consequences of cancer and its treatments. Effective patient education—that engages people optimally in monitoring and managing symptoms and side effects—is imperative for patient safety.

Patients who are engaged in their care have better experiences and outcomes⁷ through improved physical and mental health^{8,9} and early identification of potentially life-threatening complications.³ A scoping review¹⁰ explored terms for patient involvement (eg, compliance, adherence, empowerment) and concluded that patient engagement is the best term for capturing power, motivation, and active choice to become knowledgeable and involved in their health care. Cancer nurses need to understand conditions that either hinder or promote patients' engagement in their taking control of their care to maximize physical, psychological, and social well-being.

Epstein and Street's patient-centered communication in cancer care (PCC)¹¹ model (Table 1) helps to articulate how nurses can

* Address correspondence to: Dr Catherine Oakley, Guy's and St Thomas' NHS Foundation Trust, Guy's Hospital, Level 4 Bermondsey Wing, London, SE1 9RT UK.

E-mail address: Catherine.oakley@gstt.nhs.uk (C. Oakley).

† Co-authors.

TABLE 1
Patient Centered Communication in Cancer Care (PCC) Model Applied to the Role of the Nurse in Patient Education and Engagement.

Mediating Domains of Patient-clinician communication
Fostering healing relationships: Therapeutic, trusting relationships between patients and nurses are likely to increase patient engagement in self-care activities.
Exchanging information: Information delivery should be guided by patients and build on baseline knowledge and an understanding of beliefs. Tools to enhance engagement include: diaries; information sheets; alert cards; short films, traffic light symptom reporting tools; apps and group patient and carer education.
Responding to emotions: Nurses should elicit and address concerns before delivering information. Depression, anxiety, and fears about dying can hinder information uptake.
Managing uncertainty: Uncertainty and the associated fears of recurrence, disease progression and potential for limited life can reduce patient engagement. Nurses can assist through clarity eg, about treatment plans, likely side effects and side effect management to prepare for life during treatment.
Making decisions: Most patients prefer to make treatment-related decisions in partnership with clinicians through weighing up the pros, cons and their personal beliefs. Nurses can support shared decision making by ensuring patients and their families are well informed about the risks and benefits of treatment.
Enabling self-management: Emotional, social, and demographic factors can impact on patient engagement. Nurses can enable patients to be active and responsible participants in their care through strategies including goal setting and preparation to manage and monitor symptoms and administer medications.
Potential Moderating Factors Carer engagement, older people, fatalism, having advanced disease and being bereaved.

positively engage with patients to promote better outcomes. The model incorporates six domains representing core-mediating functions of patient-clinician communication (Fostering healing relationships, Exchanging information, Responding to emotions, Managing uncertainty, Making decisions, and Enabling self-management) and additional factors moderating patient-centered communication and health outcomes.

Domain 1: Fostering Healing Relationships

The PCC model suggests that therapeutic relationships between health professionals and patients embodying trust, honesty, openness, and disclosure increase patients' likelihood of engaging with self-care activities. Communication between professionals and patients can vary according to respective genders, ethnicity, age, and educational status. If they fail to connect, patients can be passive and submissive during consultations.¹² Further, some services themselves can feel impersonal; chemotherapy services have been likened to a factory by patients.³

Studies show patients' reluctance to contact clinicians they do not have a good relationship with^{3,13} or who have previously dismissed concerns.¹⁴ Others sometimes avoid bothering staff perceived as busy^{3,13,14} and/or contacting emergency helplines, opting instead to wait to see a member of staff they connect with.³

Patient engagement can be encouraged through nurses' active listening, inviting patients to tell their stories and through relationship building over time.¹⁰ Cancer nurses are ideally placed to develop trusting and healing relationships with patients through connecting with them by enacting these behaviors, answering questions, solving problems and concerns, and delivering information in a measured and constructive manner across multiple consultations; information that includes key safety-related matters messages.

Domain 2: Exchanging Information

This domain suggests that most people with cancer and their families seek information—and by providing it, cancer nurses help relationship building, patient decision-making, and uncertainty

management. Importantly, nurses should determine patients' baseline knowledge and beliefs before imparting new information, be guided by patients' and families' agendas and concerns, and enhance motivation and confidence to engage in care.¹⁵ This is aided when the rationale for any desired behaviors is explained.^{3,16}

However, one UK study¹⁷ incorporating nonparticipant observation of interactions between clinicians, patients, and carers during chemotherapy, and another exploring delayed presentation with neutropenic sepsis,³ found information delivery by clinicians often dispassionate, checklist-driven, assuming compliance, and poorly tailored to need or preference. This may be reflective of busy clinical environments that can compromise effective information exchange.¹⁸

Timing of information giving is also important. For example, patients can find information about neutropenic sepsis emotive and hard to assimilate before starting chemotherapy. It brings home the seriousness of a diagnosis and can exacerbate fears of dying.³ This needs to be factored into information exchange; information needs to be delivered sensitively, slowly, and returned to. Oakley et al (2017)³ determined that many patients prefer to understand clearly sepsis risk, actions to mitigate risk, and likely scenarios should sepsis manifest. Engagement can be engendered through asking what patients already know and what most concerns or frightens them. It is also important to assess barriers to learning including literacy, language, hearing, sight, or mental health issues, alongside any preferred learning media (eg, paper, online, audio, or video). Whatever the media, use of clear straightforward language is imperative, and summarizing is wise.

Tools that can enhance patient engagement include diaries, information sheets, alert cards, short films, and traffic light symptom reporting tools.^{19,20} Recent innovations include patient apps²¹ and group consultations (these can be guided by learning facilitators); group discussions and exercises enable peer-to-peer learning that patients and families can find therapeutic and helpful for coping. Delivery by learning facilitators, or by patient apps, can save cancer nursing resources.²² It is also important to recognize the affect of increased use of oral therapies in the metastatic breast cancer setting. The responsibility for self-medication and reporting of side effects can be overwhelming for patients who are also trying to manage the symptoms of disease and SACT side effects. The tools mentioned here can help with patient engagement with oral therapies.^{20,23,24}

Domain 3: Responding to Emotions

Responding to emotions is necessary as fears about cancer and treatments, and low mental mood generally, hinder successful information uptake and can lead to patients' avoidance and poor engagement in advisable self-care.³

Low mental affect is common in patients with cancer. Global estimates suggest around 32% of people living with breast cancer (any stage) experience depression,²⁵ and 20–58% experience anxiety around diagnosis and during treatment.²⁶

As mentioned, learning about neutropenic sepsis can heighten treatment-related fears and fear of dying from cancer; these can be exacerbated in people with advanced disease and likely enhanced by concerned clinicians repeatedly stressing the urgency of calling the hospital if becoming unwell.³ Oakley et al (2017) found that repeated iteration of urgency related to neutropenic sepsis failed to translate into enhanced self-care or timely help-seeking.³

Thus, this domain suggests nurses should elicit emotional concerns before delivering information. This may be helped by reviewing patients' notes to gain understanding of the person, their concerns, and context of their lives before starting nursing interactions. Checklists should be used with care as they can convey lack of empathy and hinder rapport and patient–professional connection.^{3,17}

Domain 4: Managing Uncertainty

Uncertainty is the inability to accurately predict future illness events or outcomes.²⁷ Cancer brings uncertainty, with its associated fear of recurrence or disease progression and potential for limiting life. For people with advanced breast cancer dealing with uncertainty is an ongoing concern, impacting on many areas of their lives.²⁸ Inability to predict symptoms, appraise them as normal/abnormal, and fears for the future evoke considerable distress,^{27,29} diminish sense of control,^{27,30-32} and engagement in self-care.³ Uncertainty can unwittingly be exacerbated by clinicians discussing uncertainty over complex therapeutic decisions, equivocal treatment outcomes, and revisions to staging or treatment required following new clinical information (to name but a few).

Patients with cancer value certainty and those undergoing treatment typically seek clarity over treatment plans, likely side effects, and side effect management³³⁻³⁵ to prepare for life during it.^{13,34,36,37} The PCC managing uncertainty domain suggests cancer nurses should target information to individual patient needs and develop an agreed-on plan for dealing with uncertainty. Importantly, relationships with carers, other patients, and clinicians can also modify uncertainty.³⁸

Domain 5: Making Decisions

This domain suggests that most patients prefer to make treatment-related decisions in partnership with clinicians through weighing up pros and cons and their personal beliefs. This requires them to be well informed about the benefits and risks of treatments and party to open and honest discussions with clinicians about them. Historically, paternalism presided, and clinicians were observed underplaying the seriousness of cancer or treatment side effects,^{39,40} potentially resulting in mismatches between patients' needs for information and that provided by clinicians. One study reported a clear mismatch between patients' need for chemotherapy information and that provided by clinicians regarding chances of cure (94.6% versus 34.3%) and effectiveness of chemotherapy in other patients (90% versus 48.5%).⁴¹

However, it appears that challenges persist over patients being sufficiently informed of either treatment risks, notably regarding neutropenic sepsis, and patients' personal risk of developing it^{3,42} or that advanced cancer can develop after primary breast cancer treatment.⁴³ Arguably, clinicians may limit information provided about severe treatment side effects (eg, sepsis) over fear of patients refusing chemotherapy if fully explained.³ However, some patients have believed that they suffered unnecessarily due to having insufficient information on managing chemotherapy symptoms.⁴⁴ This research highlights significant issues related to informed consent for chemotherapy and risks associated with power imbalances in favor of clinicians during decision-making consultations.¹²

Intentional nonadherence to oral chemotherapy self-medication for breast cancer has been associated with women feeling out of control with treatment-related decision making.⁴⁵ This has clear consequences for patient safety and treatment efficacy; patient engagement in treatment decision-making can be critical. Tobiana et al (2020) in their review¹⁰ highlighted the value of providing ongoing information about health status, investigations, and procedures and helping weigh alternative choices during decision-making.

Domain 6: Enabling Self-Management

The domain focuses on clinicians' roles in enabling patients to be active and responsible participants in care. Research suggests these roles can be enacted better in people with cancer. The study referenced previously³ showed clinicians' style of information giving about neutropenic sepsis tended to frighten patients and inhibit their

taking active responsibility for it.³ A seminal piece of work by Bandura (1988)⁴⁶ identified the association between negative stress reactions (like being anxious/frightened) and reduced ability to perform. It is important to recognize that carers (family members/friends) are equally affected by treatment-related stress and that this can affect how they perform in their caring role when deciding whether and when to seek help for an unwell patient.

Conditions for enabling self-management appear inadequate at present. Engaging patients and their carers in patients' care can, however, be complex. Interventions for enabling it are generally underpinned by behavior change theory, but there is limited evidence of their effectiveness. Further, there is little training for cancer nurses in enabling self-management, and organizations generally do not facilitate the integration of patient engagement into routine care.^{47,48} Vulnerable or marginalized groups may find it especially difficult to engage in care. A systematic review of self-management interventions for older people with cancer concluded that frailty compromises the ability to engage with self-management during cancer and that few self-management interventions have been developed for this group.⁴⁹

Cancer nurses should assess patients' ability for self-management, such as language issues, comorbidities, physical symptoms, educational and social status, normal routine and priorities, carer support, emotional ability to engage, and prior illness experience. Further, Tobiana et al's review (2020)¹⁰ identified health professionals' actions that encourage patients' self-management including helping patients with goal-setting, providing support in monitoring symptoms, and preparing them well for administering medications. Support in monitoring symptoms can be enhanced through providing patients/carers with traffic light tools^{20,24} that can help patients and carers recognize and report potentially life-threatening treatment-related symptoms. Traffic light tools can clarify symptom severity and frequency and legitimize symptoms to report.^{20,24} Further, patient and carer group consultations can also encourage self-management through facilitating mutual support, patient recall, and collective (patient/carers) engagement in symptom management.²²

Moderating Factors

The PCC model also includes factors that moderate relationships between patient-centered communication and outcomes, such as age and extent of disease. Additional moderators have been identified by Oakley et al (2017)³ including carer-engagement, bereavement, and fatalistic beliefs.

Carer Engagement

A cancer diagnosis not only affects people with cancer, it is also devastating for family and friends. All are thrown into adopting new roles and responsibilities. For carers, these can range from providing emotional support to practical and financial help and/or physical care. Each phase from diagnosis through treatment to living with and beyond cancer brings its own challenge for carers; carers are important for helping patients' engagement in self-care to manage illness and associated treatment and to seek help in a timely fashion should patients become unwell. However, research suggests that a third of people with cancer are not asked by clinicians about their support network.⁵⁰ Without asking, health professionals will be unaware of support structures available to, and needed by, patients as they progress through treatment.

Studies of information giving by health professionals to people with cancer,⁵¹⁻⁵³ and to those undergoing chemotherapy specifically,^{54,55} have determined that information delivery is predominantly patient centric. Carers report feeling excluded from dialogue and lacking confidence in supporting patients to recognize and report symptoms of disease progression or treatment toxicity or

knowing who to call in case of emergency.^{17,51,55,56} 'Feeling unprepared to care'^{51,52,57,58} and not knowing how to support patients³ are common carer concerns.

Cancer nurses can address this by encouraging carers to attend appointments and identify ways of supporting patients. In some cases, it can help if patients share information with carers if the latter cannot attend appointments and give permission to carers to seek help for them if needed. Oakley et al's³ 2017 study found patients ill-prepared to attend the hospital at short notice during chemotherapy; they suggested patients and carers are guided in preparing for rapid unplanned hospital attendance if needed. Consideration may be required for childcare and work responsibilities.

Older People

Cancer nurses must understand the needs of older people with cancer and their carers in order to intervene appropriately to enable self-management and maintain patient safety. Interventions for older people need to be co-designed with them to ensure their success and incorporate media (eg, self-management care plans, films, nurse-structured home programs) that are fitting for them.⁴⁹ Choice must be based on need and ability, for example, older adults may/may not embrace technology.⁵⁹⁻⁶¹

Further, older people may have specific age-related concerns regarding treatment and care that need to be established and understood. A recent study suggests that relaying the summary of a comprehensive geriatric assessment to oncologists planning and discussing care with patients and their carers⁶² may enhance patient and carer-centered communication about age-related issues. Skills are needed by healthcare professionals to communicate effectively with older people—to ensure that the quality of communication is not compromised alongside patient safety. Korc-Grodzicki et al (2020)² developed a training module to enhance the quality of communication with older people with cancer with cognitive difficulties. Patients with a degree of cognitive deficit (and compromised hearing) can find complex self-management instructions difficult to assimilate and act upon.

Fatalism

Oakley et al (2017)³ suggest that fatalism should be incorporated within the PCC model. Cancer fatalism is the pessimistic belief that the presence of cancer means inevitable death.⁶³⁻⁶⁶ Research has identified an association between fatalism and late presentation with locally advanced breast cancer⁶⁷ and in low uptake of breast and cervical cancer screening in ethnic minorities generally and in Black women particularly.^{63,64} Religiosity is likely to play a part through their placing faith in a higher entity,^{3,66} relying upon this entity to direct health choices,⁶⁴ and ultimately a belief in some that if cancer is God's will, then it is not for them to intervene.^{3,68} These beliefs may manifest in people with high fatalism not engaging with cancer information⁶⁴ or being less likely to engage actively with cancer nurses and other health professionals in decisions regarding their care.⁶⁷

Having Advanced Breast Cancer and Being Bereaved

Advanced breast cancer alone or alongside bereavement could moderate patient-centered communication. Patients with advanced disease can express passivity during clinicians' consultations on hearing bad disease-related news.^{3,29,33,37} An international study about preferences for control in decision-making among 1490 people with advanced cancer (including advanced breast cancer) showed high satisfaction with information sharing and decision-making.⁶⁹ Most preferred shared or active decision-making, with 23% preferring passive decision control, significant predictors of which included higher

education, higher performance status, and country of birth (eg, Brazil, Singapore, South Africa, Jordan).⁶⁹ The caveat is that desire for involvement and satisfaction are likely to vary according to country, perceived status of physicians, and actual level of hierarchy in physician–patient relationship.

Research has shown a clear association between grief following bereavement and delayed patient presentation with breast cancer, including malignant breast cancer wounds.⁷⁰ Avoidance can be heightened when grief is complicated by beliefs that physicians have been unable to help family members who died from breast cancer.⁷⁰ Avoiding help-seeking for concerning symptoms during chemotherapy has also been reported in people with advanced disease and/or who have been bereaved.³ This may be because these people are particularly fearful of neutropenic sepsis and adopt avoidance and normalizing behaviors to cope. Oakley et al (2017)³ propose that therapeutic relationships with clinicians are highly valued by these patients and that they are more likely to contact clinicians they feel connected with if sepsis develops. Importantly, this may cause a delay in treating neutropenic sepsis if the chosen clinician is not immediately available.

Conclusion

Perhaps unsurprisingly, there are common, complex, and often intersecting reasons why patients with cancer may not engage well with, assimilate, or act on information that nurses provide. Nurses need to develop well-honed skills to address these issues, thereby ensuring patients have a positive experience of care and that clinical outcomes are maximized. It is well known that health professionals' own behaviors and approaches are critical to enabling patient engagement and the adoption of important self-management actions.

The PCC model provides an excellent guide to the domains that are important for effective patient education and engagement. The relational and emotional aspects of imparting information, the timing and pacing of it, and the focus on patients'/carers' needs and capacity for receiving it are important, as are ways to reduce uncertainty and provide information at a time and pace and using approaches that suit individuals. It is noteworthy that interventions to enhance patient/carers' adoption of desired self-management strategies are being developed, largely based on behavior change theory, but evidence regarding effectiveness is lacking. More research is needed to help guide health professionals generally, and cancer nurses specifically, in this aspect of caregiving. Well-honed skills are needed, and this does have implications for education. We need to be clear across curricula that nurses and other healthcare professionals have sufficient preparation and training to ensure that individual needs for information and support—a patient-centered approach to communication—become the norm. This could radically enhance patients' and carers' experiences and outcomes of care through their being more engaged in, and responsible for, it.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

1. Cancer Research UK. Breast Cancer Incidence (Invasive) Statistics. Cancer Research UK. <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/incidence-invasive#heading-One>.
2. Korc-Grodzicki B, et al. Addressing the quality of communication with older cancer patients with cognitive deficits: development of a communication skills training module. *Palliat Support Care*. 2020;18:419–424.

3. Oakley C, et al. Avoidant conversations about death by clinicians cause delays in reporting of neutropenic sepsis: grounded theory study. *Psycho-oncology*. 2017;26:1505–1512.
4. Mandelzweig L, et al. Perceptual, social, and behavioral factors associated with delays in seeking medical care in patients with symptoms of acute stroke. *Stroke*. 2006;37:1248–1253.
5. Thureson M, et al. Thoughts, actions, and factors associated with prehospital delay in patients with acute coronary syndrome. *Heart Lung J Acute Crit Care*. 2007; 36:398–409.
6. Mackintosh JE, et al. Why people do, or do not, immediately contact emergency medical services following the onset of acute stroke: qualitative interview study. *PLoS One*. 2012;7:e46124.
7. Barello S, Graffigna G, Vegni E. Patient engagement as an emerging challenge for healthcare services: mapping the literature. *Nurs Res Pract*. 2012;2012: 905934.
8. Park M, et al. Patient- and family-centered care interventions for improving the quality of health care: a review of systematic reviews. *Int J Nurs Stud*. 2018;87:69–83.
9. Sharma AE, et al. Patient engagement in health care safety: an overview of mixed-quality evidence. *Health Aff (Millwood)*. 2018;37:1813–1820.
10. Tobiano G, Jerofke-Owen T, Marshall AP. Promoting patient engagement: a scoping review of actions that align with the interactive care model. *Scand J Caring Sci*. 2021;35:722–741.
11. Epstein RM, Street RL. Patient-centered communication in cancer care: promoting healing and reducing suffering. *Natl Cancer Inst*. 2007.
12. Fallowfield L, et al. Gaps in care and support for patients with advanced breast cancer: a report from the Advanced Breast Cancer Global Alliance. *JCO Glob Oncol*. 2021;976–984. <https://doi.org/10.1200/go.21.00045>.
13. Pedersen B, Kottved DP, Nielsen LL. Living with side effects from cancer treatment: a challenge to target information. *Scand J Caring Sci*. 2013;27:715–723.
14. Dubois S, Loisel CG. Cancer informational support and health care service use among individuals newly diagnosed: a mixed methods approach. *J Eval Clin Pract*. 2009;15:346–359.
15. Lin C, Cohen E, Livingston PM, Botti M. Perceptions of patient participation in symptom management: a qualitative study with cancer patients, doctors, and nurses. *J Adv Nurs*. 2019;75:412–422.
16. Tolotti A, et al. Patient engagement in oncology practice: a qualitative study on patients' and nurses' perspectives. *Int J Environ Res Public Health*. 2022;19:11644.
17. Ream E, et al. Informal carers' experiences and needs when supporting patients through chemotherapy: a mixed method study. *Eur J Cancer Care (Engl)*. 2013;22:797–806.
18. Chan EA, Wong F, Cheung MY, Lam W. Patients' perceptions of their experiences with nurse-patient communication in oncology settings: a focused ethnographic study. *PLoS One*. 2018;13:1–17.
19. Macmillan Cancer Support. Cancer Treatment Alert Kit. <https://be.macmillan.org.uk/be/p-26166-cancer-treatment-alert-kit.aspx>.
20. Oakley C, Johnson J, Deepro M. Development of a patient-held diary for oral chemotherapy. *Cancer Nurs Pract*. 2008. <https://doi.org/10.7748/cnp2008.07.7.6.31.c6603>.
21. Richards R, Kinnerley P, Brain K, Staffurth J, Wood F. The preferences of patients with cancer regarding apps to help meet their illness-related information needs: qualitative interview study. *JMIR mHealth uHealth*. 2019;7:e14187.
22. Rowland E, Oakley C. A multi-method study exploring the acceptability and benefits of developing a group pre-treatment consultation for people receiving systemic anticancer therapy. *Cancer Nurs Pract*. 2023. In press.
23. Mawhinney MW, Warden J, Stoner N. The oral education clinic: a pharmacist- and nurse-led clinic to support patients starting oral systemic anti-cancer treatments. *J Oncol Pharm Pract*. 2019;25:449–453.
24. Oakley C, Johnson J, Ream E. Developing an intervention for cancer patients prescribed oral chemotherapy: a generic patient diary. *Eur J Cancer Care (Engl)*. 2010;19:21–28.
25. Pilevarzadeh M, et al. Global prevalence of depression among breast cancer patients: a systematic review and meta-analysis. *Breast Cancer Res Treat*. 2019; 176:519–533.
26. Harris J, Cornelius V, Ream E, Cheevers K, Armes J. Anxiety after completion of treatment for early-stage breast cancer: a systematic review to identify candidate predictors and evaluate multivariable model development. *Support Care Cancer*. 2017;25:2321–2333.
27. Mishel MH, Braden CJ. Finding meaning: antecedents of uncertainty in illness. *Nurs Res*. 1988;37:98–103.
28. Greco C. The uncertain presence: experiences of living with metastatic breast cancer. *Med Anthropol*. 2022;41:129–140.
29. Pollock K, Cox K, Howard P, Wilson E, Moghaddam N. Service user experiences of information delivery after a diagnosis of cancer: a qualitative study. *Support Care Cancer*. 2008;16:963–973.
30. Broadbridge E, et al. Facilitating psychological adjustment for breast cancer patients through empathic communication and uncertainty reduction. *Patient Educ Couns*. 2023;114: 107791.
31. Mishel MH. Reconceptualization of the uncertainty in illness theory. *Image J Nurs Scholarsh*. 1990;22:256–262.
32. Stiegelis HE, et al. The impact of an informational self-management intervention on the association between control and illness uncertainty before and psychological distress after radiotherapy. *Psycho-oncology*. 2004;13:248–259.
33. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med*. 1980;92:832–836.
34. Skalla KA, Bakitas M, Furstenberg CT, Ahles T, Henderson JV. Patients' need for information about cancer therapy. *Oncol Nurs Forum*. 2004;31:313–319.
35. Kav S, Tokdemir G, Tasdemir R, Yalili A, Dinc D. Patients with cancer and their relatives' beliefs, information needs and information-seeking behavior about cancer and treatment. *Asian Pac J Cancer Prev*. 2012;13:6027–6032.
36. Ream E, Richardson A. The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. *Eur J Cancer Care (Engl)*. 1996;5:132–138.
37. Mills ME, Sullivan K. The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *J Clin Nurs*. 1999;8:631–642.
38. Stree RL, et al. Managing uncertainty and responding to difficult emotions: cancer patients' perspectives on clinician response during the COVID-19 pandemic. *Patient Educ Couns*. 2022;105:2137–2144.
39. Lerman C, et al. Effects of coping style and relaxation on cancer chemotherapy side effects and emotional responses. *Cancer Nurs*. 1990;13:308–315.
40. Cowley L, Heyman B, Stanton M, Milner SJ. How women receiving adjuvant chemotherapy for breast cancer cope with their treatment: a risk management perspective. *J Adv Nurs*. 2000;31:314–321.
41. McCaughan EM, Thompson KA. Information needs of cancer patients receiving chemotherapy at a day-case unit in Northern Ireland. *J Clin Nurs*. 2000;9:851–858.
42. Leonard K. A European survey relating to cancer therapy and neutropenic infections: nurse and patient viewpoints. *Eur J Oncol Nurs*. 2012;16:380–386.
43. Fallowfield L, et al. Living with metastatic breast cancer (LIMBER): experiences, quality of life, gaps in information, care and support of patients in the UK. *Support Care Cancer*. 2023;31:459.
44. Mazar KM, et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. *J Clin Oncol*. 2012;30:1784–1790.
45. Atkins L, Fallowfield L. Intentional and non-intentional non-adherence to medication amongst breast cancer patients. *Eur J Cancer*. 2006;42:2271–2276.
46. Bandura A. Self-efficacy conception of anxiety. *Anxiety Res*. 1988;1:77–98.
47. Cuthbert CA, et al. Self-management interventions for cancer survivors: a systematic review and evaluation of intervention content and theories. *Psycho-oncology*. 2019;28:2119–2140.
48. Kantilal K, et al. Facilitating healthcare practitioners to deliver self-management support in adult cancer survivors: a realist review. *Res Soc Adm Pharm*. 2022; 18:3870–3883.
49. Melbye H, Joensen L, Risor MB, Halvorsen PA. Symptoms of respiratory tract infection and associated care-seeking in subjects with and without obstructive lung disease: the Tromsø Study. *Tromsø 6. BMC Pulm Med*. 2012;12:51.
50. Macmillan Cancer Support. Facing the Fight Alone, Isolation Among Cancer Patients. [https://www.macmillan.org.uk/documents/aboutus/mac13970_isolated_cancer_patients_media_reportfinal.pdf\(2013\)](https://www.macmillan.org.uk/documents/aboutus/mac13970_isolated_cancer_patients_media_reportfinal.pdf(2013)).
51. Morris SM, Thomas C. The carer's place in the cancer situation: where does the carer stand in the medical setting? *Eur J Cancer Care (Engl)*. 2001;10:87–95.
52. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin*. 2010;60:317–339.
53. McCarthy B. Family members of patients with cancer: what they know, how they know and what they want to know. *Eur J Oncol Nurs*. 2011;15:428–441.
54. Hilton BA, Crawford JA, Tarko MA. Men's perspectives on individual and family coping with their wives' breast cancer and chemotherapy. *West J Nurs Res*. 2000;22:438–459.
55. Tsiakanas V, et al. Enhancing the experience of carers in the chemotherapy outpatient setting: an exploratory randomised controlled trial to test impact, acceptability and feasibility of a complex intervention co-designed by carers and staff. *Support Care Cancer*. 2015;23:3069–3080.
56. The Royal College of Radiologists. Cancer Patients in Crisis: Responding to Unmet Needs. Report of a Working Party. 2012. <https://www.rcr.ac.uk/publication/cancer-patients-crisis-responding-urgent-needs>.
57. Northouse L, Williams A-L, Given B, McCorkle R. Psychosocial care for family caregivers of patients with cancer. *J Clin Oncol*. 2012;30:1227–1234.
58. Macmillan Cancer Support. More Than a Million: Understanding the UK carers of people with cancer - a report by Ipsos Mori for Macmillan Cancer Support. 2011. https://www.macmillan.org.uk/documents/cancerinfo/ifsomeoneelsehascancer/more_than_a_million.pdf.
59. Hasnan S, Aggarwal S, Mohammadi L, Koczwar B. Barriers and enablers of uptake and adherence to digital health interventions in older patients with cancer: a systematic review. *J Geriatr Oncol*. 2022;13:1084–1091.
60. Wilson K, Gates JR, Vijaykumar S, Morgan DJ. Understanding older adults' use of social technology and the factors influencing use. *Ageing Soc*. 2023;43:222–245.
61. Vlooswijk C, et al. Differences in Internet use and eHealth needs of adolescent and young adult versus older cancer patients; results from the PROFILES Registry. *Cancers (Basel)*. 2021;13.
62. Mohile SG, et al. Communication with older patients with cancer using geriatric assessment. *JAMA Oncol*. 2020;6:196.
63. Skinner CS, Champion V, Menon U, Seshadri R. Racial and educational differences in mammography-related perceptions among 1,336 nonadherent women. *J Psychosoc Oncol*. 2002;20:1–18.
64. Behbakht K, Lynch A, Teal S, Degeest K, Massad S. Social and cultural barriers to Papanicolaou test screening in an urban population. *Obstet Gynecol*. 2004;104:1355–1361.
65. Powe BD, Hamilton J, Brooks P. Perceptions of cancer fatalism and cancer knowledge: a comparison of older and younger African American women. *J Psychosoc Oncol*. 2006;24:1–13.
66. Cassibba R, et al. The role of attachment to God in secular and religious/spiritual ways of coping with a serious disease. *Ment Health Relig Cult*. 2014; 17:252–261.

67. Mohamed IE, Skeel Williams K, Tamburrino M, Wryobeck J, Carter S. Understanding locally advanced breast cancer: what influences a woman's decision to delay treatment? *Prev Med (Baltim)*. 2005;41:399–405.
68. Jones C, et al. A systematic review of barriers to early presentation and diagnosis with breast cancer among black women. *BMJ Open*. 2014;4:e004076.
69. Yennurajalingam S, et al. Decisional control preferences among patients with advanced cancer: an international multicenter cross-sectional survey. *Palliat Med*. 2018;32:870–880.
70. Lund-Nielsen B, Midtgaard J, Rørth M, Gottrup F, Adamsen L. An avalanche of ignoring: a qualitative study of health care avoidance in women with malignant breast cancer wounds. *Cancer Nurs*. 2011;34:277–285.