

Cancer Care That Reflects Real Patient Experiences

When people think about cancer care, they often think about diagnosis, treatment, and survival. These are the parts that are visible, discussed, and measured. But alongside this, there is another layer of experience that unfolds more quietly. It is seen in how people make sense of what is happening to them, how they manage daily life during treatment, and how they adjust afterward. This is what lived experience means in cancer care. It is about going through illness, not just being treated for it.

Over time, research from different parts of the world has begun to show that this experience is closely connected to care. It shapes how people understand information, how they make decisions, and how they continue with treatment. Studies by *Yael Busnel and Anugrah Robby* show that patients often carry emotional, practical, and informational needs that are not always visible within routine care structures.

As more people live longer with cancer, this connection has become more important. Care is not only about managing disease. It is also about supporting how people live through it. This is why lived experience is increasingly valued in cancer care design. It helps systems understand what patients go through in their daily lives and how care can better respond to that reality. It also raises an important question. If lived experience can improve how care is designed, how can it be meaningfully included in systems that have traditionally focused on clinical outcomes?

When Emotional Needs Are Not Fully Supported

Many patients move through cancer treatment with strong clinical support but still find it difficult to manage what they are feeling. Research suggests that emotional needs such as fear, uncertainty, and the need for reassurance are common across different stages of care. Research, including work by *Yael Busnel* on peer support in oncology, shows that many patients report unmet emotional needs even while receiving appropriate treatment.

This becomes easier to understand when we look at how people describe their experiences. *Anugrah Robby* shows that patients often experience uncertainty and emotional strain, especially when outcomes are unclear. These are not occasional experiences. They are part of how many people live through cancer.

Some approaches are beginning to respond to these experiences. Peer support programs, developed through participatory research, allow patients to speak with others who have gone through similar experiences. *Busnel's* study shows that peer support helps patients feel less alone and improves their quality of life.

Other approaches focus on expression. *Nina H. Russin* describes how activities such as drawing, painting, and guided creative expression help patients process emotions and reduce distress. These are structured interventions where trained facilitators guide patients through creative work, helping them express thoughts that may be difficult to put into words.

These approaches show that including emotional needs in care helps patients feel more supported. Care becomes about not only treatment but also helping people live through what they are experiencing.

When What Is Measured Does Not Reflect Daily Life

In many healthcare systems, success is measured through clinical outcomes. Care teams often look at how treatment is working, how the disease is responding, and how survival is improving. These are important measures, but they do not always show how a person is feeling day to day.

Patients often care about different things. They may want to know if they will be able to manage daily activities, how much fatigue they might experience, or how treatment will affect their quality of life. This is where patient-reported outcomes become important.

Judith F. Baumhauer shows that value-based healthcare focuses on what patients care about. Patient-reported outcomes include information about pain, physical function, emotional well-being, and daily life, shared directly by patients.

This helps doctors and healthcare systems understand the broader impact of treatment by listening to how patients describe their own experiences.

At a broader level, *Julie Cayrol's* global survey work aims to collect large-scale data on how people experience cancer across different countries, including social, emotional, and financial aspects of living with cancer.

When care systems begin to measure these experiences, they can respond more closely to what patients go through.

When Care Does Not Fit into Everyday Life

Jessica A. Thomas combined findings from several studies and patient experiences to understand how lifestyle changes work in real life. This type of review helps understand not only whether an intervention works, but also how people experience it. The study found that many patients found it difficult to follow lifestyle recommendations consistently, even when they understood the benefits. These recommendations often included maintaining regular physical activity, following a balanced diet, and managing weight during treatment, which many patients found difficult due to fatigue, side effects, and daily responsibilities.

This is where participatory research becomes important. *Tanay* shows that when patients are involved in developing interventions, those interventions become more practical and easier to follow. For example, patients helped shape programs by suggesting flexible schedules, simpler routines, and adjustments that could fit around treatment cycles and low-energy days.

John Kildea used a similar approach while developing a patient-centered digital portal with patient input. In this study, patients helped design a digital platform that provided access to

medical information, appointment schedules, and communication tools. Because patients contributed to its design, the platform became easier to use and more relevant to their needs.

These examples show that when patients are involved in design, interventions become more practical. They fit into daily life more easily, so people are more likely to use them regularly.

When Context Shapes Access and Experience

Where people live and the resources they have shape their experience of cancer care. Research shows that access to care, awareness, and support systems can vary widely across regions.

Dannell Boatman worked with communities in Appalachia to design cervical cancer interventions that people could understand and use. By involving community members, researchers used familiar language and culturally relevant messaging, making it easier for people to understand information and take part in screening and prevention.

Renske Visser explored cancer care in prison settings and showed that people in these settings often struggle to access care and support. By including people with lived experience of prison, the research identified practical ways to improve care in these settings, such as clearer communication of symptoms, better coordination of referrals, and more consistent access to basic screening and follow-up care.

These studies show that context shapes how people experience care. When care systems take this into account, they can design more inclusive and effective solutions.

When Support Reduces After Treatment

Many patients find that support reduces significantly after treatment ends. While clinical care may conclude, the experience of cancer often continues.

Len Lichtenfeld explains that patients often need ongoing support for managing long-term effects such as fatigue, anxiety, and physical changes. Survivorship planning aims to address this by providing structured follow-up care.

This includes regular monitoring, psychological support, and guidance on returning to daily life. However, research shows that these plans are not always consistently implemented.

Recognizing lived experience helps address this gap. It reminds us that care should not stop at treatment. It should continue in ways that support patients as they adjust to life after cancer.

When Patients Are Not Fully Involved in Decisions

Cancer treatment involves important decisions that affect a person's life in significant ways. Patients need clear information, time to think, and the ability to express their preferences.

Mary C. Politi shows that when patients are involved in decisions, they feel more informed and more confident about their choices. They are also more likely to follow treatment plans. This often includes open discussions with doctors, asking questions, and choosing between options based on what feels manageable in their daily lives.

This approach respects patients as individuals who understand their own lives. It allows care to align with what matters to them, whether that is quality of life, treatment intensity, or long-term goals.

Including patients in decisions is not only helpful. It is a way of recognizing their dignity and role in their own care.

When Some Experiences Are Still Overlooked

Even as care systems improve, they still miss some experiences. Caregivers, for example, play a central role but often receive limited support.

Ablavi Adani-Ifè shows that caregivers often feel emotionally stressed and face financial pressure while supporting patients. Many also manage daily responsibilities, hospital visits, and decision-making alongside their own well-being, which can become difficult to sustain over time. Their needs are closely connected to patient care, yet they are not always addressed directly.

Dana M. Womack shows that patients are often not aware of supportive services that could help them. This can include services such as counselling, pain management support, or integrative care options, which remain underused simply because people do not know they are available.

Rob Kessels highlights that traditional research methods do not always capture real-world patient experiences. New approaches aim to better reflect how patients experience care over time, including changes in daily routines, emotional needs, and long-term adjustment after treatment.

These findings show that while progress is being made, there is still a need to include a wider range of experiences in both care and research.

Where Gaps Still Remain

Across these studies, a clear pattern emerges. Lived experience is increasingly recognized, but not yet fully integrated. Some interventions exist, but they are not always consistently available. Some experiences are studied, but others remain less visible. Bridging this gap requires not only awareness but also sustained effort to include lived experience in everyday care.

What Can Improve Cancer Care Systems

Improving cancer care requires changes that are practical and grounded in evidence. Integrating patient-reported outcomes into routine care can help ensure that patient experiences are consistently considered. Encouraging co-design in healthcare programs can make services more relevant. Expanding peer support and community-based care can improve access.

Strengthening communication practices and shared decision-making approaches within healthcare settings can further support patient involvement. Including caregivers in care planning can support the broader care environment. Improving research methods can ensure that findings reflect real-world experiences.

These changes build on existing systems while making them more responsive to the people they serve.

Understanding the Human Side of Care

At its core, the shift toward lived experience is about understanding care more fully. It recognizes that patients are not only receiving treatment but also living through a complex experience.

This perspective emphasizes dignity, respect, and the importance of listening. It also shows that care must reflect different lived realities, not just one standard experience.

When lived experience is included, care becomes more complete. It brings together clinical knowledge and human understanding.

Sanjeevani: Bringing Lived Experience into Everyday Care

Within this broader shift toward recognizing lived experience, the work of Sanjeevani...Life Beyond Cancer reflects how these ideas take shape in everyday care. It brings attention to what patients and caregivers go through alongside treatment and creates opportunities where these experiences can be shared, understood, and supported in a more grounded way.

One way this becomes visible is through the monthly support group meetings. Held across hospitals and community settings, these gatherings bring patients and caregivers together in a space where conversations can unfold more openly. Alongside interactions with healthcare professionals and sessions on lifestyle practices, there is room for people to speak about what they are going through in their own words. As individuals share their journeys, others begin to recognize parts of their own journey in them. This sense of familiarity often makes it easier to ask questions, express concerns, and engage more actively in care.

Across different cities, these meetings reflect how shared spaces can shape experience. In Kolkata, at Chittaranjan National Cancer Institute, patients and caregivers came together to discuss managing side effects, pain, and daily challenges during treatment. In Delhi, a support

group meeting created a quieter moment of connection through meditation and simple shared activities. In Manipal, conversations focused on managing physical changes such as fatigue, low immunity, and appetite loss, while also offering practical guidance on nutrition and follow-up care. In Goraj, discussions around treatment, early diagnosis, and patient concerns created a setting where questions could be addressed more directly. While each setting is different, what remains consistent is the opportunity for people to listen, reflect, and feel less alone in what they are experiencing.

Programs like Srjan extend this support over a longer period of time. By bringing together nutrition, breathing practices, movement, and mental well-being, the program allows individuals to engage with different aspects of care at their own pace. The focus is not on making large changes all at once, but on building small, consistent practices that can be carried into daily life. Over time, this steady engagement begins to influence how people experience their symptoms and emotions. Concerns such as fatigue, sleep difficulties, and anxiety often become more manageable, while feelings of fear or uncertainty begin to ease gradually. These changes do not remove challenges, but they help individuals respond to them with a greater sense of balance.

In-hospital counselling adds another important layer to this approach. Within clinical environments, where information, decisions, and treatment processes move quickly, it is not always easy to pause and process what one is feeling. Counselling offers that pause. It allows patients and families to speak about fear, confusion, or emotional strain in a way that feels natural and accepted. These conversations sit alongside medical care, helping individuals feel heard and understood without taking away from the focus on treatment.

Satori, Sanjeevani's holistic healing initiative, brings these elements together in a more integrated way. It creates a structured yet gentle space where individuals can reconnect with their bodies and emotions without feeling the need to present themselves in a certain way. Through guided sessions that include nutrition, breathing practices, and mental health support, participants can engage with their well-being in a way that feels manageable. The intention is not to push people toward a fixed idea of strength, but to support them in building a steadier relationship with their own experience.

As individuals move through these sessions, many begin to find small shifts in how they relate to their health and daily life. Managing side effects, adjusting routines, and responding to emotional changes becomes a more gradual and supported process. What often changes is not the situation itself, but the way people feel within it. There is more room for rest, for expression, and for uncertainty to exist without pressure.

Taken together, these efforts show how lived experience can be included in care in ways that feel natural and consistent. Support moves beyond a single moment or intervention. It continues alongside treatment and recovery. In doing so, it helps care feel more connected to the realities of everyday life, where people are managing illness and finding ways to live through it.

Conclusion

Cancer care continues to evolve, shaped by both scientific progress and a deeper understanding of patient experience. Research across different settings shows that lived experience shapes how people understand and move through care.

As systems begin to include this perspective, care becomes more responsive and more meaningful. It supports not only treatment but also how people live through and beyond cancer.

The challenge ahead is to ensure that this approach becomes part of everyday practice. When care includes lived experience consistently, it reflects what people actually go through.

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