

When Cancer Changes the Self: Reconstructing Illness Identity in the Digital Age

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Abstract: *Cancer is not experienced solely as a biological condition. Diagnosis and treatment can alter bodily experience, daily routine, relationships, expectations for the future, and the continuity through which individuals understand themselves. Although psychosocial oncology has examined coping, adjustment, social support, and psychological distress, the question of how cancer becomes incorporated into a person's sense of self warrants focused attention. This conceptual paper examines illness identity as a central lens for understanding psychological adaptation to cancer. Drawing on foundational work on biographical disruption and loss of self, plus cancer-specific research on illness identity, the paper proposes that adaptation may involve an ongoing negotiation between illness and self rather than a simple return to a pre-cancer identity. The paper distinguishes this proposed process of illness-identity negotiation from established illness-identity concepts: the framework offered here is a conceptual proposition developed by the author, not an established empirical typology. Possible forms of negotiation- illness dominance, identity resistance, identity integration, and identity reconstruction—are therefore presented as sensitizing concepts for future research rather than fixed categories. The paper also considers the digital environment as a social context in which individuals encounter illness information, peer experiences, online communities, and representations of cancer. Such environments may provide resources for identity reconstruction while also introducing comparison and socially available expectations about what it means to live with cancer. The paper concludes that psychosocial oncology may benefit from attending not only to whether patients are coping with cancer, but also to how they are negotiating who they are in relation to it.*

Keywords: cancer; illness identity; identity disruption; identity reconstruction; biographical disruption; psychological adaptation; digital context

1. Introduction

A cancer diagnosis can represent a profound interruption in the ordinary organisation of a person's life. Beyond the immediate medical implications, cancer may alter bodily experience, daily routines, relationships, responsibilities, and expectations about the future. In this sense, illness may become significant not simply because it produces symptoms or treatment demands, but because it can challenge the continuity through which individuals understand themselves. Foundational work on chronic illness has described this disruption as a biographical disturbance: illness can interrupt assumptions about the body, everyday life, and the future, requiring individuals to reconsider the organization and meaning of their lives (Bury, 1982).

Charmaz (1983) similarly highlighted loss of self as a fundamental dimension of suffering in chronic illness, describing how former self-images may become difficult to sustain when illness restricts everyday life and alters social relationships. Subsequent work has further examined how chronic illness can produce identity dilemmas and require people to preserve valued elements of self while accommodating change (Charmaz, 1994, 1995). These perspectives are particularly relevant to cancer, where diagnosis can be experienced as an assault on biography and identity rather than as an isolated medical event.

Cancer-specific research supports this perspective. Qualitative work with people newly diagnosed with colorectal cancer has shown that cancer can disrupt biographies and threaten identity, while also demonstrating that such disruption is not experienced uniformly by all patients (Hubbard et al., 2010). Research on gynecological cancer has explicitly examined illness identity and suggested that the way cancer becomes represented within the self may

remain relevant even during recovery and periods of apparent physical improvement (Bradley et al., 2001). More directly, Palmer-Wackerly et al. (2018) found that cancer patients negotiated illness identity across personal, relational, and communal identity frames, including situations in which different identity positions came into conflict.

Despite these developments, illness identity is conceptually diverse. A recent integrative review of health- and illness-identity literature found that illness identity has been conceptualized in different ways across disciplines, including as a sense of self as ill, as a way of acting in relation to illness, and as a socially judged identity (Pelters et al., 2024). This conceptual diversity is important for cancer research because it suggests that illness identity should not be treated as a single, fixed psychological state.

The present paper therefore focuses on one construct- illness identity- and develops a narrower conceptual argument around it. The central proposition is that psychological adaptation to cancer may be understood partly as a process of negotiating the relationship between illness and self. The paper does not propose that all patients pass through the same identity stages, nor does it claim that the proposed forms of negotiation are established categories. Rather, illness-dominant identity, identity resistance, identity integration, and identity reconstruction are offered as conceptual possibilities that can organize future research.

2. Conceptualizing Illness Identity

Illness identity concerns the relationship between a health condition and a person's sense of self. The construct is broader than simply acknowledging a diagnosis. It concerns how individuals understand themselves in relation to being ill, how illness is incorporated into self-understanding, and how the

social meanings attached to illness become relevant to identity. Pelters et al. (2024), in an integrative review of 64 articles, demonstrated that illness identity has been conceptualized in multiple ways. One important strand concerns illness identity as a sense of self as an ill person, while other approaches emphasize what people do in relation to illness or how illness identities are socially evaluated.

This conceptual variation suggests that illness identity should be treated as constructed and processual rather than as an essential characteristic. A person does not necessarily become 'a cancer patient' in a complete or permanent sense simply because a diagnosis has occurred. Instead, cancer may become more or less salient within different contexts and at different points in the illness trajectory. Palmer-Wackerly et al. (2018) illustrate this process through their study of 46 cancer patients, showing that participants could experience separate, aligned, or conflicting identity frames while making treatment decisions.

The distinction between illness and identity is therefore central. Cancer is a medical condition, but 'having cancer' and 'understanding oneself primarily through cancer' are not equivalent experiences. Similarly, resisting a cancer identity does not necessarily mean denying the medical reality of the disease. An individual may accept the diagnosis while resisting the idea that the diagnosis should define who they are.

On this basis, the present paper uses illness identity to refer broadly to the way individuals understand, incorporate, resist, or position illness in relation to their sense of self. This definition is deliberately compatible with the wider literature while allowing the paper to focus specifically on cancer and psychological adaptation.

3. Cancer, Biographical Disruption, and the Threat to Self

Bury's (1982) concept of biographical disruption provides a useful starting point for understanding why cancer can affect identity. Chronic illness can interrupt taken-for-granted assumptions about everyday life and the future. The disruption is not necessarily located only in the disease itself; it emerges through the relationship between illness and a person's biography. Cancer may therefore challenge the continuity between who an individual understood themselves to be before diagnosis and who they are able to be during treatment or survivorship.

Charmaz's (1983) work adds a more explicitly identity-focused dimension. When illness restricts activity, creates dependency, produces social isolation, or changes how others respond to the person, former self-images may become increasingly difficult to maintain. The resulting experience can involve a loss of valued identities without an immediately available alternative. Charmaz (1995) subsequently described serious chronic illness as undermining the unity between body and self and emphasised adaptation as a process of altering life and self to accommodate bodily losses and limitations.

These ideas are especially relevant to cancer because the illness may alter several identity-relevant domains

simultaneously. The body can change through disease and treatment; occupational and family roles may be interrupted; independence may be reduced; and assumptions about the future can become uncertain. A person who previously understood themselves primarily through work, parenthood, partnership, physical activity, or independence may suddenly have to navigate the patient role alongside, or sometimes in place of, these identities.

Cancer-specific evidence illustrates this process. Hubbard et al. (2010) examined 18 people with colorectal cancer across the first year following diagnosis and found that participants engaged in biographical work in the context of threats to identity. Importantly, the authors caution against assuming that cancer produces the same kind of biographical disruption for everyone. This variability strengthens rather than weakens the illness-identity perspective: if identity disruption is individually and socially negotiated, then adaptation cannot be understood only through the objective severity of the disease.

4. From Identity Disruption to Identity Reconstruction

Identity disruption does not necessarily mean that identity remains permanently fractured. A central idea carried forward from the original manuscript is that psychological adaptation may involve reconstruction rather than restoration. Restoration implies a return to an earlier state, whereas reconstruction allows for the possibility that the person may develop a changed but coherent relationship with the self.

This distinction is consistent with the broader chronic-illness literature. Charmaz (1994) described processes through which chronically ill individuals attempted to preserve a sense of coherence while accommodating uncertainty, illness, and loss. Charmaz (1995) similarly conceptualized adaptation as altering life and self in response to bodily limitations. In cancer, this may involve retaining valued elements of the pre-diagnosis self while incorporating experiences that have emerged through diagnosis, treatment, recovery, recurrence, or survivorship.

Continuity within change is therefore a useful conceptual lens. Continuity does not require the individual to remain unchanged. Rather, it refers to the possibility of experiencing a meaningful thread between past, present, and anticipated future selves. An individual may recognise that cancer has changed them while simultaneously maintaining that cancer is not the totality of who they are. Illness can become part of the biography without necessarily becoming the entire biography.

Recent illness-identity scholarship also supports understanding identity as processual. Pelters et al. (2024) note that illness identities can involve disruption and change across time, including movement between subject positions such as patient, survivor, or post-illness identity. The present paper builds on this process orientation by proposing that psychological adaptation may be understood through the ongoing negotiation of how illness is positioned within the self.

5. Illness-Identity Negotiation: A Proposed Conceptual Framework

The phrase 'illness-identity negotiation' is used in this paper as a proposed conceptual framework developed by the author. It is not presented as an established model or validated theoretical construct. The purpose of the framework is to integrate existing insights about biographical disruption, illness identity, identity conflict, and reconstruction into a focused account of psychological adaptation to cancer.

The framework begins with cancer as an experience capable of disrupting previously held assumptions about the self. This disruption creates a need to negotiate the relationship between illness and identity. The negotiation may involve questions such as: How much of my identity is now occupied by cancer? Do I want to be seen primarily as a patient? Which parts of my previous identity remain important? What has changed? What can be incorporated into the self without erasing other valued identities?

Four conceptual possibilities are proposed below. They should be understood as overlapping and potentially changing positions, not sequential stages or diagnostic categories.

5.1 Illness-Dominant Identity

An illness-dominant identity describes a situation in which cancer occupies a highly salient position within self-understanding. Treatment, symptoms, medical appointments, uncertainty, and social responses may make illness difficult to separate from everyday identity. This does not mean that illness dominance is inherently pathological. Rather, it describes the extent to which the illness may organise how the person understands themselves and their daily experience.

5.2 Identity Resistance

Identity resistance refers to efforts to prevent cancer from becoming the defining feature of the self. An individual may accept the diagnosis and treatment requirements while resisting the social or psychological position of being primarily a 'cancer patient.' Such resistance may function as an attempt to preserve continuity with valued pre-illness roles and identities. It may also become challenging when illness-related limitations make complete separation from the patient role difficult.

5.3 Identity Integration

Identity integration refers to incorporating cancer into the self while retaining other valued dimensions of identity. Cancer may be acknowledged as an important life experience without replacing identities associated with family, work, relationships, interests, values, or future goals. Integration therefore differs from both illness dominance and complete resistance: the illness is recognized, but the self remains broader than the illness.

5.4 Identity Reconstruction

Identity reconstruction refers to developing a changed but coherent understanding of the self-following the disruption

produced by cancer. The reconstructed identity may contain elements of the pre-cancer self as well as meanings that emerged through the illness experience. Reconstruction is therefore not equivalent to 'becoming a different person'; it is the development of a workable sense of continuity while acknowledging meaningful change.

These four possibilities should not be treated as mutually exclusive. A person may resist illness identity at one point, experience illness as dominant during intensive treatment, and later integrate the experience into a broader reconstructed identity. The framework therefore treats illness identity as dynamic and context-sensitive rather than fixed.

6. Illness Identity and Social Relationships

Illness identity is not constructed in isolation. Identity is relational, and cancer can alter how people are positioned by family members, partners, friends, and healthcare professionals. Palmer-Wackerly et al. (2018) demonstrated that cancer patients negotiated illness identity across personal, relational, and communal identity frames. This suggests that the question 'Who am I with cancer?' cannot be separated completely from the question 'Who am I in relation to other people now that I have cancer?'

Social responses can either support or complicate identity reconstruction. Family members may provide essential support while also changing the degree of independence available to the patient. The patient may appreciate care while simultaneously experiencing frustration if others begin to see them primarily through the illness. Thus, caregiving and social support are relevant here not as independent constructs but because they form part of the social environment within which illness identity is negotiated.

Illness identity can also affect interactions with healthcare systems. Macdonald et al. (2016) argued that illness identities can be important to how people understand and navigate healthcare access. Sulik (2009), examining women with breast cancer, showed how biomedical knowledge and technological surveillance could become incorporated into a 'technoscientific illness identity.' These findings demonstrate that illness identity may be shaped not only by subjective experience but also by institutional, biomedical, and social environments.

7. Illness Identity in the Digital Age

Digital environments add another social context to illness-identity negotiation. People affected by cancer increasingly encounter online communities, patient stories, health information, social-media content, and peer experiences. Research on online cancer communities shows that patients and relatives share informational and emotional content and use these spaces to connect with others experiencing cancer (Ziebland et al., 2017; van Eenbergen et al., 2017).

Importantly for the present argument, digital spaces may also influence identity. Harkin et al. (2017), in a qualitative study of people affected by cancer who used online communities, found that participants described online relationships as contributing to a 'journey to recreate identity.' Online

communities could help individuals make sense of the disparity between their identity before cancer and their lives after diagnosis. This finding provides a particularly relevant bridge between digital experience and the illness-identity framework proposed here.

Digital environments may therefore function as spaces where illness identities are encountered, compared, tested, and potentially reconstructed. A person can observe how other patients describe themselves, how survivors narrate their lives, and how communities define what it means to be a patient or survivor. These encounters may provide validation by demonstrating that others share similar experiences. At the same time, they may introduce implicit expectations about how someone with cancer should behave or feel.

The digital context should consequently be treated as an environment surrounding illness-identity negotiation rather than as a separate psychological construct. The central question is not whether digital technology is simply beneficial or harmful. Rather, it is how the meanings, narratives, relationships, and comparison opportunities available online become part of the social context in which people understand themselves in relation to cancer.

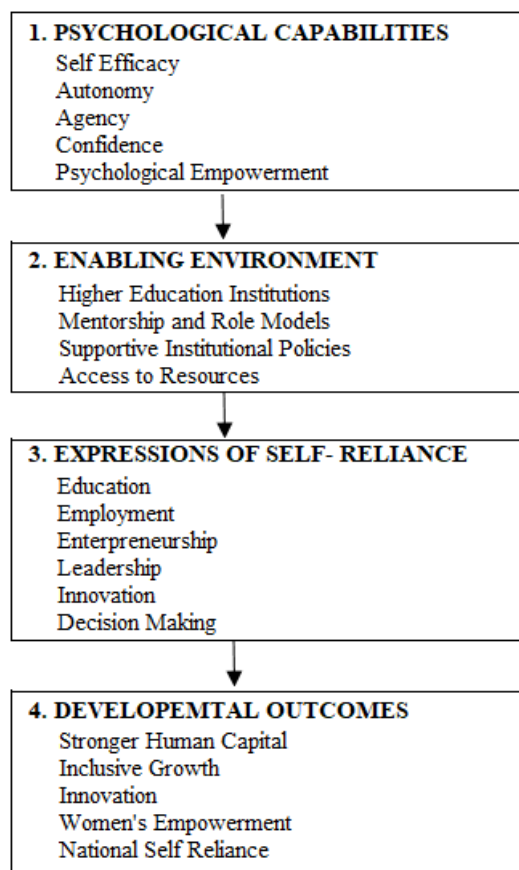


Figure 1: Conceptual Framework for Illness-Identity Negotiation in Cancer

8. Implications for Psychosocial Oncology

An illness-identity perspective may broaden psychosocial assessment beyond symptoms, distress, and coping. Clinicians could explore how patients describe themselves following diagnosis, which aspects of identity they feel have changed, which they want to preserve, and whether they feel

that others now see them differently. Such conversations may identify identity-related difficulties that are not captured by measures of psychological distress alone.

The framework also suggests that psychosocial care should avoid prescribing a single 'healthy' way of relating to illness. Not every patient will want to identify as a survivor, openly discuss cancer, or integrate the illness into every part of their self-understanding. Similarly, resistance to a patient identity should not automatically be interpreted as denial. The psychological meaning of a particular identity position must be understood in the person's broader context.

Finally, digital experiences may be relevant to psychosocial assessment. Patients may use online communities to obtain information, seek validation, compare experiences, or reconstruct a sense of normality. Asking about these experiences could help clinicians understand the wider social environment in which patients are making sense of cancer.

9. Directions for Future Research

The framework proposed here requires empirical evaluation. First, qualitative research could explore how people with different cancer diagnoses describe the relationship between cancer and identity across diagnosis, treatment, survivorship, recurrence, and palliative care. Longitudinal approaches may be particularly valuable because identity negotiation may change as the illness trajectory changes.

Second, future studies could examine whether different forms of illness-identity negotiation are associated with outcomes such as psychological distress, quality of life, social connectedness, perceived control, or treatment decision-making. However, research should avoid assuming in advance that one identity position is universally adaptive. The same identity position may serve different functions for different individuals and at different points in the illness trajectory.

Third, research should examine the digital dimension more directly. Studies could investigate whether participation in online cancer communities contributes to identity integration, identity reconstruction, or changes in the salience of the patient identity. Qualitative work could be particularly useful for understanding how people interpret patient stories and compare them with their own experiences.

Finally, cancer identity research would benefit from greater attention to cultural and social context. Family roles, independence, disclosure, stigma, and expectations surrounding illness may influence how cancer becomes incorporated into self-understanding. Comparative research across cultural contexts could therefore clarify which aspects of illness identity are broadly shared and which are socially situated.

10. Conclusion

Cancer can disrupt more than physical health. It can challenge the continuity of self by altering bodily experience, everyday roles, relationships, and expectations about the future. Foundational work on chronic illness and emerging cancer-

specific research indicate that identity is an important dimension through which illness is experienced and understood.

This paper has proposed illness-identity negotiation as a conceptual lens for understanding psychological adaptation to cancer. The framework does not assume that individuals move through fixed stages. Instead, it suggests that people may negotiate the place of cancer within themselves through varying combinations of illness, salience, resistance, integration, and reconstruction.

The central proposition is therefore not that cancer must be incorporated into identity, nor that it must be kept separate from identity. Rather, psychological adaptation may involve developing a personally meaningful relationship between illness and self. In the digital age, this negotiation occurs within an expanded social environment in which individuals encounter other patients, illness narratives, information, and representations of survivorship. Understanding that process may help psychosocial oncology move beyond asking only whether patients are coping and toward asking how they are reconstructing who they are while living with cancer.

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