

Review

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[Valentina Zoboli](#) , [Stefano Botti](#) * , Daniela Manzo , [Federica Olivazzi](#) , Manuel Gotti

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Review

Redefining Caregiver and Patient Resilience in Hematologic Malignancies: A Narrative Review

Valentina Zoboli ¹, Stefano Botti ^{2,*}, Daniela Manzo ³, Federica Olivazzi ⁴ and Manuel Gotti ¹

¹ Division of Hematology, Fondazione IRCCS Policlinico San Matteo, viale Golgi 19, 27100 Pavia, Italy

² Hematology Unit, Oncology and Advanced Technology Department, Azienda USL-IRCCS of Reggio Emilia, via Amendola 2, 42122 Reggio Emilia, Italy

³ Hematology Unit, Onco-hematology Department, Santo Spirito Hospital-ASL di Pescara, via Fonte Romana 8, 65124 Pescara, Italy

⁴ Hematology Unit, Onco-hematology Department, ASST Spedali Civili di Brescia, Piazzale Spedali Civili 1, 25123 Brescia, Italy

* Correspondence: stefano.botti@ausl.re.it; Tel.: +39 0522296661

Abstract

Background: In hematologic malignancies, treatment allocation and outcome prediction are traditionally driven by clinical and biological parameters. However, growing evidence suggests that non-clinical factors—such as psychosocial context, caregiver availability, organizational support, and digital health integration—play a pivotal role in patients' ability to tolerate and adhere to complex therapeutic pathways. The concept of “resilience” may offer a more comprehensive framework to capture this multidimensional readiness to treatment. **Methods:** we conducted a narrative review of the literature focusing on patient and caregiver resilience in hematologic settings. PubMed, Scopus, and Web of Science were searched for studies published in English over the last 15 years, addressing clinical, psychosocial, organizational, and contextual determinants influencing treatment tolerance, continuity of care, and outcomes in hematology. **Results:** the literature highlights resilience as a dynamic construct shaped by clinical fitness, psychological resources, caregiver competence, social and family context, healthcare system organization, and access to supportive technologies such as telemedicine. Several domains emerged as recurrent determinants of resilience, yet no standardized, integrated assessment tool is currently available in routine hematologic practice. **Conclusions:** resilience in hematology should be reframed as a multidimensional, context-dependent construct extending beyond traditional clinical fitness. Incorporating resilience-oriented assessment into clinical workflows may improve treatment personalization, optimize resource allocation, and enhance patient- and caregiver-centered care. Future research should focus on developing pragmatic, clinically applicable tools to operationalize resilience in real-world hematologic settings.

Keywords: resilience; support; hematologic malignancies; caregiver; treatment tolerance; multidimensional framework; decision-making

1. Introduction

The management of hematologic malignancies has undergone a profound transformation over the last two decades. Advances in diagnostic accuracy, risk stratification, and therapeutic options have significantly improved survival outcomes across multiple disease entities [1]. However, these achievements have also led to increasing complexity in treatment pathways, which often require prolonged therapies, strict adherence to schedules, close monitoring, and a high degree of patient engagement. In this context, traditional criteria used to define treatment eligibility—primarily based on age, comorbidities, and performance status—appear increasingly insufficient to capture the real-world capacity of patients to tolerate and complete modern hematologic treatments [2,3].

Clinical decision-making in hematology continues to rely heavily on the concept of “fitness,” a construct largely derived from physiological and functional parameters [4]. While this approach is essential for estimating treatment-related risks, it overlooks a broad range of non-clinical determinants that strongly influence therapeutic feasibility and outcomes. Psychological resilience, cognitive resources, caregiver support, social stability, and healthcare system organization all contribute substantially to the patient’s ability to navigate complex therapeutic journeys, yet these elements are rarely assessed in a structured or systematic manner [5].

Emerging evidence suggests that treatment discontinuation, dose reductions, unplanned hospitalizations, and poor adherence are often driven not only by biological frailty but also by contextual vulnerabilities [6]. In hematologic settings, where therapies are frequently intensive and long-lasting, the role of caregivers becomes particularly relevant. Caregivers often act as informal care coordinators, supporting symptom monitoring, treatment compliance, and access to healthcare services [7,8]. Their availability, competence, and psychosocial well-being may therefore directly impact patient outcomes, positioning caregiver-related factors as integral components of the therapeutic process rather than peripheral elements [9].

In parallel, organizational and system-level factors have gained increasing relevance. Access to specialized centers, continuity of care, availability of supportive services, and integration of telemedicine have been shown to influence treatment delivery and patient experience. These aspects highlight the need for a broader conceptual framework that extends beyond individual clinical characteristics and incorporates the interaction between patients, caregivers, and healthcare systems [10].

Within this evolving landscape, the concept of resilience has emerged as a potential unifying paradigm. Unlike fitness, resilience is inherently dynamic and multidimensional, encompassing the capacity of individuals and their surrounding context to adapt to stressors, maintain functional stability, and recover from treatment-related challenges. Although widely explored in psychological and sociological research [11], resilience remains inconsistently defined and operationalized in hematologic care, limiting its translation into clinical practice.

The aim of this narrative review is to explore how resilience has been conceptualized and applied in hematologic settings, with particular attention to patient-, caregiver-, and system-related determinants. By synthesizing the available literature, we seek to propose a multidimensional framework of resilience that may support more holistic clinical decision-making and foster the development of pragmatic assessment tools suitable for real-world hematology practice.

Although systematic or scoping reviews are typically preferred when clearly defined outcome measures and homogeneous constructs are available, the concept of resilience in hematologic care remains theoretically fragmented and operationally undefined. Given the heterogeneity of definitions, settings, and methodological approaches identified in the literature [12], a narrative review was considered the most appropriate methodological approach to explore conceptual boundaries, identify recurring domains, and generate a clinically meaningful interpretative framework.

2. Materials and Methods

This review was aimed at exploring the concept of resilience in hematologic care, with a specific focus on patient-, caregiver-, and healthcare system-related determinants influencing treatment tolerance, continuity of care, and real-world clinical outcomes. A narrative approach was selected to allow a comprehensive and flexible synthesis of heterogeneous evidence emerging from clinical, psychosocial, organizational, and digital health literature.

A structured literature search was conducted across three electronic databases: PubMed, Scopus, and Web of Science. The search covered articles published in English over the last 15 years. Keywords and Medical Subject Headings (MeSH), when applicable, were combined using Boolean operators and included terms related to hematology and resilience, such as hematologic malignancies, resilience, treatment tolerance, caregiver, psychosocial factors, organizational factors, and

telemedicine. Reference lists of relevant articles were also screened to identify additional pertinent studies.

Studies were considered eligible if they addressed one or more determinants of resilience in adult patients with hematologic diseases or their caregivers, including clinical, psychological, social, organizational, or technological aspects influencing treatment feasibility or care trajectories. Both qualitative and quantitative studies, as well as reviews and consensus papers, were included to capture the multidimensional nature of the topic. Studies focusing exclusively on pediatric populations or unrelated to hematologic care were excluded.

Data extraction focused on study characteristics, resilience-related determinants, and contextual influences on treatment feasibility. Given the heterogeneity of study designs and outcome measures, a qualitative synthesis approach was adopted. Findings were grouped into thematic domains reflecting recurrent determinants of resilience, including clinical and functional status, psychological and emotional resources, caregiver-related factors, social and family context, healthcare organization, and digital health integration.

The review process was iterative in nature, reflecting the exploratory objective of clarifying the conceptual boundaries of resilience in hematologic care. Initial search cycles primarily focused on patient-level determinants; however, caregiver- and system-level influences consistently emerged as integral components. The search strategy was therefore expanded to include organizational and digital health perspectives. The iterative search and thematic grouping were continued until conceptual redundancy was observed and no substantially new resilience domains emerged. At this stage, thematic sufficiency was considered achieved for the purpose of constructing the proposed framework.

Based on the synthesis of the selected literature, an interpretative framework was developed to conceptualize resilience as a dynamic, multidimensional construct in hematologic care. Rather than aiming for quantitative aggregation, the review sought to identify converging themes and practical implications for clinical decision-making, with the goal of informing future research and the development of clinically applicable assessment tools.

3. Results

For the purpose of this review, resilience was conceptualized as the dynamic capacity of patients, caregivers, and healthcare systems to adapt to treatment-related stressors while maintaining functional continuity of care. This definition was selected among multiple existing psychological and sociological conceptualizations of resilience because it aligns with the clinical realities of hematologic practice, where treatment feasibility depends on interactions between biological, psychosocial, and organizational determinants.

The literature analysis revealed resilience as a multidimensional construct emerging from the interaction between individual patient characteristics, caregiver-related factors, and healthcare system organization. Across the included studies, resilience was rarely defined through a single parameter; rather, it appeared as the cumulative result of multiple domains influencing treatment tolerance, adherence, and continuity of care in hematologic settings. Six major thematic domains consistently emerged.

3.1. Clinical and Functional Determinants

Clinical and functional status represented the most frequently explored dimension of resilience. Traditional indicators such as performance status, comorbidity burden, organ function, and baseline functional autonomy were commonly associated with treatment feasibility and risk of complications. However, several studies emphasized that these parameters alone failed to explain variability in treatment tolerance and outcomes. Functional decline, when present, often interacted with non-clinical factors, amplifying vulnerability during intensive or prolonged therapies [13–15].

In real-world hematologic practice, a substantial proportion of patients fall into a “borderline fitness” category, where clinical parameters do not clearly support either full-intensity treatment or

de-escalated strategies. In such scenarios, decision-making frequently extends beyond physiological metrics and incorporates contextual elements, including caregiver reliability, access to rapid medical evaluation, and the patient's capacity to manage treatment-related toxicities at home. The absence of structured tools to integrate these determinants may result in either over-treatment of socially vulnerable patients or under-treatment of individuals who are biologically fit but perceived as fragile. These observations suggest that clinical fitness should be interpreted within a broader resilience-informed framework, particularly when therapeutic decisions involve high-intensity regimens or narrow therapeutic margins.

3.2. Psychological and Emotional Factors

Psychological resilience, encompassing coping strategies, emotional regulation, and perceived self-efficacy, emerged as a critical determinant of patients' ability to endure complex treatment pathways. Anxiety, depressive symptoms, and cognitive overload were repeatedly associated with reduced adherence, increased symptom burden, and higher healthcare utilization [16]. Conversely, adaptive coping mechanisms and emotional stability were linked to improved engagement with care and better management of treatment-related stressors.

3.3. Caregiver-Related Factors

Caregiver availability and competence were consistently identified as central components of resilience in hematologic care. Caregivers frequently assumed responsibilities related to symptom monitoring, medication management, logistical coordination, and emotional support. Studies highlighted that caregiver strain, limited health literacy, or lack of support networks could negatively affect patient outcomes, whereas well-supported and adequately informed caregivers enhanced treatment continuity and reduced unplanned care disruptions [17–19].

3.4. Social and Family Context

Social stability, family structure, and socioeconomic conditions contributed significantly to resilience. Patients embedded in supportive family environments demonstrated greater capacity to manage treatment demands and recover from adverse events. In contrast, social isolation, financial stress, and unstable living conditions were associated with increased vulnerability, delayed care-seeking behaviors, and reduced access to supportive resources [20].

3.5. Organizational Factors

Healthcare organization emerged as a key, yet often under-recognized, determinant of resilience. Continuity of care, accessibility of specialized services, multidisciplinary coordination, and clear communication pathways influence patients' ability to navigate complex therapeutic trajectories. Fragmented care models—characterized by delayed referrals, inconsistent communication between inpatient and outpatient settings, or unclear responsibility transitions—may increase the cognitive and logistical burden placed on patients and caregivers, thereby reducing resilience even in clinically fit individuals.

Timely access to diagnostic procedures, specialist consultations, supportive services, and urgent evaluation of treatment-related complications represents another critical dimension. In hematologic malignancies, where therapeutic windows can be narrow and toxicity profiles unpredictable, delays in care access may directly affect treatment feasibility and outcomes. Conversely, integrated care pathways with defined access channels and rapid-response mechanisms may buffer contextual vulnerabilities and enhance patients' capacity to sustain intensive therapeutic regimens [21–23]. These findings suggest that resilience is not solely a patient-level attribute but also reflects the structural robustness of the healthcare system where the care is delivering.

3.6. Digital Health and Telemedicine

The integration of digital health tools, including telemedicine and remote monitoring, was increasingly described as a resilience-enhancing factor. These technologies support timely symptom reporting, reduce logistical barriers, and facilitate communication between patients, caregivers, and healthcare teams. In particular, patient-reported outcome (PRO)-based monitoring systems have demonstrated the potential to improve early detection of treatment-related toxicities, enabling proactive clinical intervention before complications escalate. Remote toxicity management platforms and structured tele-triage models may reduce avoidable emergency visits and unplanned hospitalizations, thereby preserving treatment continuity in patients undergoing intensive or prolonged therapies [21,24,25]. Teleconsultations and digital communication tools further contribute to resilience by decreasing geographic and organizational constraints, especially for patients managed predominantly in outpatient settings. However, the effectiveness of these interventions depends on digital literacy, caregiver involvement, and integration within established clinical workflows. When embedded within coordinated care models, digital health solutions may function not merely as technological adjuncts but as structural enablers of resilience-oriented hematologic care.

Across domains, no study provided an integrated operational model combining biological, psychosocial, and organizational determinants. Most available evidence remains fragmented, with limited cross-domain integration. This fragmentation reinforces the need for a multidimensional interpretative framework capable of capturing resilience as a system-level construct rather than an individual attribute [26,27].

Table 1. Domains of Resilience in Hematologic Care.

Reference	Domain	Key Elements	Clinical Implications
13,14,15	Clinical and functional status	Performance status, comorbidity burden, organ function, baseline functional autonomy	Influences treatment intensity selection, risk of toxicity, and need for supportive interventions
16	Psychological and emotional factors	Coping strategies, emotional regulation, anxiety, depressive symptoms, cognitive load	Affects treatment adherence, symptom perception, and patient engagement throughout the therapeutic pathway
17,18,19	Caregiver-related factors	Caregiver availability, health literacy, organizational skills, caregiver burden	Impacts treatment continuity, home-based care feasibility, and early detection of complications
20	Social and family context	Family support, social network, living conditions, socioeconomic stability	Modulates access to care, ability to manage complex regimens, and resilience to treatment-related stressors
21,22,23	Organizational factors	Continuity of care, multidisciplinary coordination, access to specialized services, communication pathways	Determines care fragmentation versus integration, influencing unplanned hospitalizations and care experience
21,24,25	Digital health and telemedicine	Teleconsultations, remote monitoring, digital communication tools	Reduces logistical barriers, enhances monitoring, and supports long-term outpatient management

4. Discussion

This narrative review highlights resilience as a multidimensional and context-dependent construct that cannot be adequately captured by traditional definitions of clinical fitness alone. In

hematologic care, where therapeutic strategies are increasingly complex, prolonged, and resource-intensive, resilience emerges as a key determinant of real-world treatment feasibility, continuity, and outcomes. Our findings suggest that resilience is not an intrinsic patient characteristic but rather the result of a dynamic interaction between clinical status, psychosocial resources, caregiver capacity, and healthcare system organization.

From a hematologic perspective, fitness assessments remain indispensable for estimating treatment-related risks; however, they primarily address biological vulnerability. In daily practice, hematologists frequently encounter patients who meet formal fitness criteria yet struggle to complete treatment due to non-clinical factors, as well as patients with borderline clinical profiles who successfully tolerate intensive therapies thanks to strong contextual support. This discrepancy underscores the limitations of fitness-based decision-making when applied in isolation and supports the need for broader evaluative frameworks.

A particularly relevant finding concerns the central role of caregivers in shaping resilience. In hematologic pathways—especially those involving outpatient-based regimens, long-term oral therapies, or frequent hospital access—caregivers often function as informal extensions of the healthcare team. Their ability to recognize early warning signs, manage complex medication schedules, and coordinate logistics can directly influence treatment adherence and prevent avoidable complications. Importantly, caregiver resilience is itself dependent on education, support, and integration within the care pathway, highlighting the necessity of structured caregiver assessment and engagement.

In hematologic malignancies such as aggressive lymphomas, acute leukemias, or transplant settings, treatment intensity and timing often leave limited margins for error. In these contexts, resilience may influence not only adherence but also eligibility for advanced therapeutic options. Failure to consider contextual determinants may inadvertently exclude patients who are biologically fit but socially vulnerable.

Within this context, the role of the nurse case manager appears pivotal. Positioned at the intersection between patients, caregivers, and the healthcare system, nurse case managers are uniquely equipped to identify early signs of reduced resilience, whether clinical, psychological, or organizational. Through continuous patient contact, care coordination, and education, they contribute to maintaining treatment continuity and mitigating fragmentation of care. Rather than representing an additional layer of support, case management should be viewed as an integral component of resilience-oriented hematologic care.

Organizational and system-level determinants further modulate resilience, often independently of individual patient characteristics. Fragmented care pathways, limited access to supportive services, and poor communication between care settings increase the burden placed on patients and caregivers, potentially overwhelming even those with adequate personal resources. Conversely, coordinated models of care—characterized by multidisciplinary collaboration, clear communication pathways, and continuity across settings—appear to enhance resilience by reducing uncertainty and cognitive load.

Digital health solutions and telemedicine may act as resilience multipliers within such models. By facilitating timely communication, remote monitoring, and rapid intervention, these tools can partially compensate for geographic, logistical, or organizational barriers. However, their effectiveness depends on appropriate patient and caregiver engagement and on integration into established clinical workflows, rather than stand-alone implementation.

Taken together, these findings support a shift from a static, patient-centered notion of fitness toward a dynamic, system-oriented concept of resilience. This perspective aligns closely with real-life hematologic practice, where treatment success often depends as much on care organization and support structures as on disease biology. Embedding resilience assessment into routine clinical workflows—potentially through structured, nurse-led evaluations—may enhance therapeutic personalization, optimize resource allocation, and reduce avoidable treatment disruptions.

Future research should focus on translating this conceptual framework into pragmatic tools applicable in everyday practice. Such tools should be simple, multidimensional, and designed for use within multidisciplinary teams, with particular attention to the role of nurse case managers in their implementation. By operationalizing resilience in this manner, hematologic care may move closer to truly personalized, context-aware treatment strategies that reflect the complexity of patients' real-world experiences [28–30].

4.1. Limitations

This review has limitations inherent to the narrative methodology. First, although a structured search strategy was employed, the approach was not designed to achieve exhaustive retrieval of all potentially relevant studies. Narrative reviews prioritize conceptual integration over comprehensive inclusion; therefore, some relevant publications may not have been captured.

Second, the interpretation and thematic grouping of the literature were influenced by the authors' clinical and case-management experience in hematologic settings. While this perspective enhances clinical applicability, different research teams might have emphasized alternative dimensions or organized domains differently.

Third, the concept of resilience in hematologic care lacks standardized operational definitions and validated measurement tools. As a result, the proposed framework reflects conceptual synthesis rather than empirical validation. The heterogeneity of study designs, populations, and endpoints further limits the possibility of quantitative aggregation.

Finally, although caregiver and organizational factors emerged as central components of resilience, the available literature remains uneven across domains, with stronger evidence in psychosocial oncology than in hematology-specific contexts. This imbalance may influence the relative weight attributed to certain determinants within the proposed framework.

Furthermore, most available studies originate from high-income healthcare systems, potentially limiting the transferability of the proposed framework to low-resource settings.

Despite these limitations, the narrative approach was intentionally chosen to explore conceptual boundaries and generate a clinically grounded interpretative model. The framework proposed in this review should therefore be considered a starting point for future empirical validation rather than a definitive classification.

5. Conclusions

Resilience in hematologic care represents a multidimensional construct that extends beyond traditional assessments of clinical fitness. This review highlights how treatment feasibility and continuity are not shaped only by biological and functional parameters, but also by psychological resources, caregiver capacity, social context, and healthcare system organization. Ignoring these dimensions may lead to suboptimal therapeutic decisions and increased risk of treatment discontinuation in real-world practice.

Reframing resilience as a dynamic interaction between patients, caregivers, and care systems offers a more realistic lens through which to interpret treatment tolerance and outcomes in hematology. Such an approach aligns with daily clinical experience, where the success of complex therapeutic pathways often depends on coordinated care, effective communication, and early identification of contextual vulnerabilities.

Integrating resilience-oriented evaluation into routine hematologic practice may support more personalized treatment strategies, improve allocation of supportive resources, and enhance patient and caregiver engagement. In this framework, structured, multidisciplinary, and nurse-led care models—particularly those involving case management—may play a key role in translating resilience from a conceptual construct into a practical clinical tool.

Future efforts should focus on developing pragmatic, clinically applicable instruments capable of capturing resilience in its multiple dimensions and embedding them into standard care pathways. Advancing toward resilience-informed hematologic care has the potential to improve not only

clinical outcomes, but also the quality and sustainability of care delivery in an increasingly complex therapeutic landscape.

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