

# Illness Perceptions and Illness Outcomes in Patients with Hematologic Diseases: A Narrative Review

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## Abstract

**Background:** Patients diagnosed with chronic illnesses form personalized perceptions of their conditions, which guide their coping strategies and illness outcomes. Leventhal's Common-Sense Model outlines these beliefs, including illness identity, consequences, timeline, causes and controllability. **Aims:** This narrative review aims to synthesize existing literature examining the association between illness perceptions and illness outcomes in patients with hematologic disorders. **Method:** An extensive search was conducted in Pubmed, APA PsycInfo and Web of Science databases up to December 2023. Inclusion criteria encompassed adult patients with hematologic disorders, peer-reviewed studies utilizing the Illness Perception Questionnaire (IPQ), the Revised IPQ or the Brief-IPQ in English and primary studies measuring relationships between illness perceptions and outcome variables. Eight articles met these criteria. **Results:** Among adults with hematologic diseases, including hemophilia, leukemia and cutaneous lymphoma, patients' perceptions of their disease have shown interesting associations with outcomes, like anxiety and depression levels, fatigue, psychological well-being and cancer-specific distress. In some reports, negative perceptions have been associated with poorer outcomes. **Limitations:** Published articles not indexed in the above-mentioned databases or those in the grey literature were not included. Non-English language studies were excluded, while some of the studies did not explore the relationships between illness perceptions and outcomes over time. **Conclusions:** This review highlights the relationship between illness perceptions and illness outcomes across various hematologic patient populations. Additional

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studies and longitudinal research are warranted to improve our understanding of how illness perceptions affect outcomes in hematologic disorders, aiming to improve disease management through appropriate interventions.

## Keywords

Illness Perceptions, Illness Representations, Hematologic Diseases, Illness Outcomes, Review

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## 1. Introduction

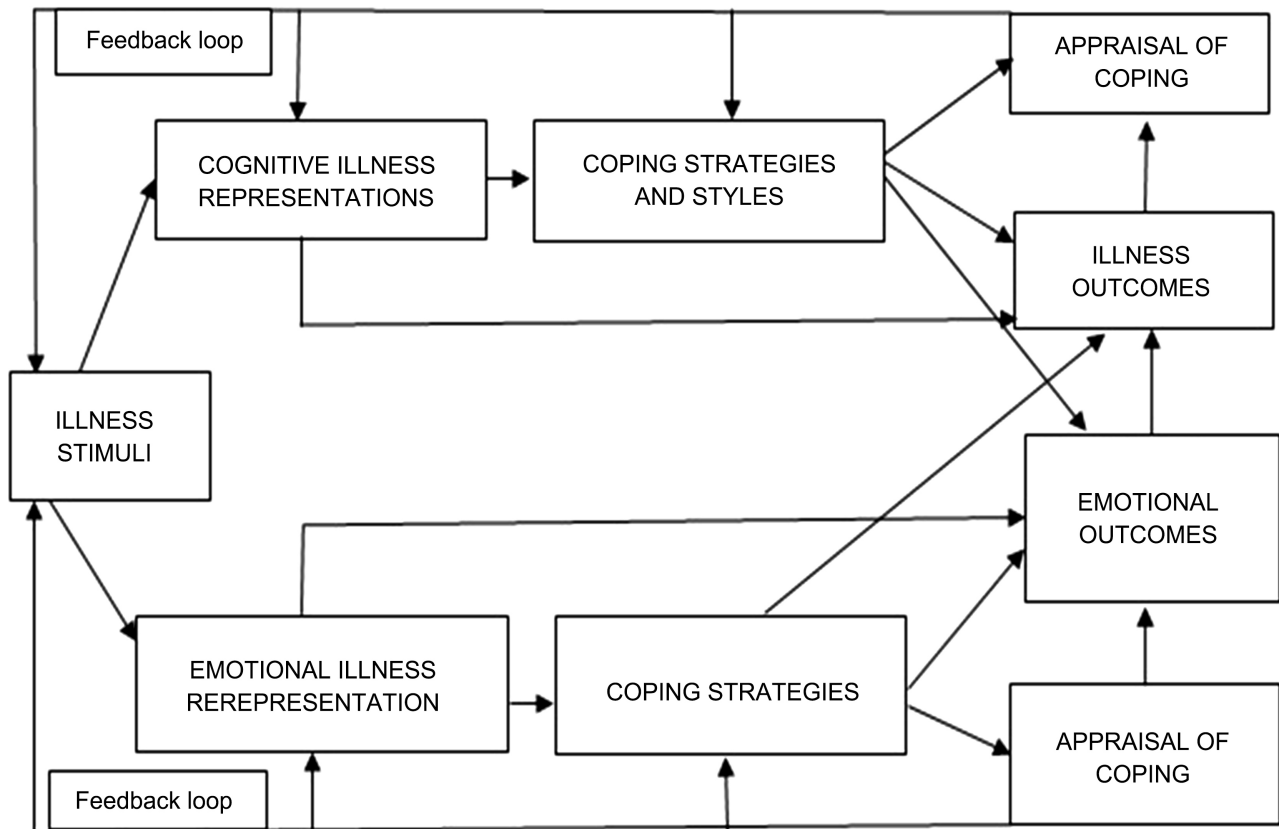
The term “hematologic disorders” refers to diseases that affect the blood cells or blood-forming organs. In this context, hematologic disorders may arise from abnormalities of the white blood cells, red blood cells, platelets, or blood coagulation and include pathological conditions of the bone marrow, spleen and lymph nodes. Hematologic disorders can be acute or chronic, genetic or acquired, malignant (cancerous), or non-malignant (benign) leading to a broad spectrum of signs and symptoms depending on the particular condition (Hoffbrand et al., 2016). For instance, patients with the genetic disorder hemophilia often experience spontaneous and recurrent bleeding in muscles and joints, which can potentially cause severe joint damage, pain and subsequent disability (Srivastava et al., 2013). Moreover, several individuals diagnosed with chronic lymphocytic leukemia, a common lymphoid malignancy, may experience little or no symptoms at diagnosis and may not need treatment for a long time (Shanafelt et al., 2009), while others may exhibit symptoms right from the outset such as fatigue, weight loss and persistent infections and require treatment promptly (Holtzer-Goor et al., 2015). Meanwhile, myelodysplastic syndromes are a heterogeneous group of hematologic malignancies associated with decreased survival. Presenting symptoms include fatigue, bleeding and infections (Sekeres & Taylor, 2022). Finally, early-stage mycosis fungoides, a hematologic malignancy of the skin, typically has a favorable survival rate (Lee, 2023), but symptoms such as pruritus and pain can also have a significant impact on a patient’s psychological status and quality of life (Nourmohammadpour et al., 2023). The treatment of hematologic disorders includes watchful waiting, transfusions, chemotherapy, or other drugs depending on the underlying disorder and even hematopoietic stem cell transplantation in the setting of hematologic malignancies (Hoffbrand et al., 2016). The challenges imposed by the symptoms and treatment of these disorders can exert a negative impact on various domains of patients’ health-related quality of life, including physical, mental and social aspects (Allart-Vorelli et al., 2015).

The concept of illness perception derives from Leventhal’s Common-Sense Model of Self-Regulation (CSM), which explores the interplay between patients’ beliefs about their condition, coping procedures and illness outcomes (Leventhal et al., 1980; Diefenbach & Leventhal, 1996; Hagger & Orbell, 2003). According to

this model, individuals facing health threats, such as chronic illnesses, construct cognitive and emotional representations of their conditions that guide subsequent coping strategies and behaviors (Bishop & Converse, 1986; Leventhal et al., 1992). These representations include five core components: identity, timeline, consequences, causes and cure/control. More specifically, illness identity refers to the name of the disease and the associated symptoms. Timeline includes the ideas of patients about the duration of the illness and its course. Consequences refer to the impact of disease on daily life as perceived by the patient, financial difficulties for example. Causes of threat consist of factors potentially contributing to the illness, for example, external factors such as infections or other predisposing conditions, or genetic factors. Controllability or curability describes beliefs about the control or cure of the disease (Leventhal et al., 1992; Petrie & Weinman, 2006). Additionally, along with the aforementioned cognitive representations, emotional ones are also formed. The latter refers to the individual's emotional reactions to the illness, such as fear and anxiety (Leventhal et al., 1992; Diefenbach & Leventhal, 1996). In addition to personal experience (e.g., symptoms), illness perceptions draw from various sources of information, including family and healthcare professionals as well as cultural knowledge about the illness (Leventhal et al., 1980; Hagger & Orbell, 2003).

The CSM is a dynamic self-regulation model, in which the formation of illness perceptions begins with the onset of symptoms and continues throughout the illness' course from diagnosis. This means that perceptions can be readjusted on many occasions during the course of the illness, depending on the disease progression, the coping procedures adopted and the appraisal of the efficacy of the latter (Leventhal et al., 2016; Hagger & Orbell, 2022). This dynamic process continues until the coping procedures can effectively manage the health threat. Patients may adopt several categories of coping behaviors and strategies ranging from seeing a doctor and adherence to medication to avoidance and denial. In addition, coping efforts seem to act as an intermediary between illness perceptions and illness outcomes, even though illness perceptions and outcomes could also be associated independently to a certain extent of the adopted coping strategies (Hagger & Orbell, 2003) (Figure 1).

Initially, CSM-based illness perceptions were measured using the Illness Perception Questionnaire (IPQ) (Weinman et al., 1996), a self-report scale that measures cognitive illness perceptions such as identity, timeline, consequences, causes and controllability or curability. The IPQ was later revised by Moss-Morris (Moss-Morris et al., 2002) into the Revised Illness Perception Questionnaire (IPQ-R), which includes additional dimensions such as coherence (how understandable the illness is to the patient), timeline cyclical (degree of symptom variability as perceived by the patient) and emotional representations (the patient's emotional response to their illness). This questionnaire also divided the control/cure component into personal control (the degree to which the patient believes they can control their condition) and treatment control (belief that the



**Figure 1.** Leventhal et al.'s (1980) Common-Sense Model of Self-Regulation (CSM) based on the modifications by Hagger & Orbell (2003).

illness can be controlled with the current treatment) dimensions. A condensed version of the IPQ-R is the Brief Illness Perception Questionnaire (B-IPQ) (Broadbent et al., 2006), a user-friendly self-report instrument that assesses cognitive (consequences, timeline, personal control, treatment control, identity, coherence and causes) and emotional (concern and emotions) representations of illness.

Several reviews, systematic reviews and meta-analyses in the context of various illnesses, such as asthma, coronary heart disease, chronic kidney disease, heart failure and multiple sclerosis, have demonstrated significant associations between illness perceptions and illness outcomes (e.g., quality of life, anxiety, depression, fatigue and psychological well-being) (Hagger & Orbell, 2003; Foxwell et al., 2013; Clarke et al., 2016; Sawyer et al., 2019; Luca et al., 2022). On the other hand, to the best of our knowledge, no previous review on the associations between illness perceptions and outcomes in hematologic diseases has been conducted.

Given the significance of the CSM in understanding the role of illness perceptions in disease management and outcomes, this review aimed to address the following question: “What is the relation between illness perceptions and illness outcomes in patients with hematologic disorders?”

## 2. Method

### 2.1. Search Strategy

To identify relevant studies for this review, an extensive literature search was performed in three different databases (PubMed, APA PsycInfo and Web of Science) on December 11, 2023. For the search, various terms pertained to “illness perceptions” (and associated terms) and “hematologic disorders” were combined using the Boolean operator “AND”. More specifically, the search algorithm included phrases such as: (“illness perception” OR “illness perceptions” OR “common-sense model” OR “illness representations” OR “illness representation” OR “disease representations” OR “disease representation” OR “disease perception” OR “disease perceptions”) AND (“Thalassemia” OR “Thalassaemia” OR “Sickle cell disease” OR “Sickle cell anemia” OR “Sickle cell anaemia” OR “Venous thrombosis” OR “Hemophilia” OR “Haemophilia” OR “Iron-Deficiency Anemia” OR “Iron-Deficiency Anaemia” OR “Immune Thrombocytopenia” OR “Hemolytic Anemia” OR “Haemolytic Anaemia” OR “Thrombotic Thrombocytopenic Purpura” OR “Aplastic Anemia” OR “Aplastic Anaemia” OR “Von Willebrand Disease” OR “Lymphoma” OR “Multiple Myeloma” OR “Myelodysplastic Syndrome” OR “Leukemia” OR “Leukaemia” OR “Myeloproliferative Neoplasms” OR “Hematologic Malignancies”).

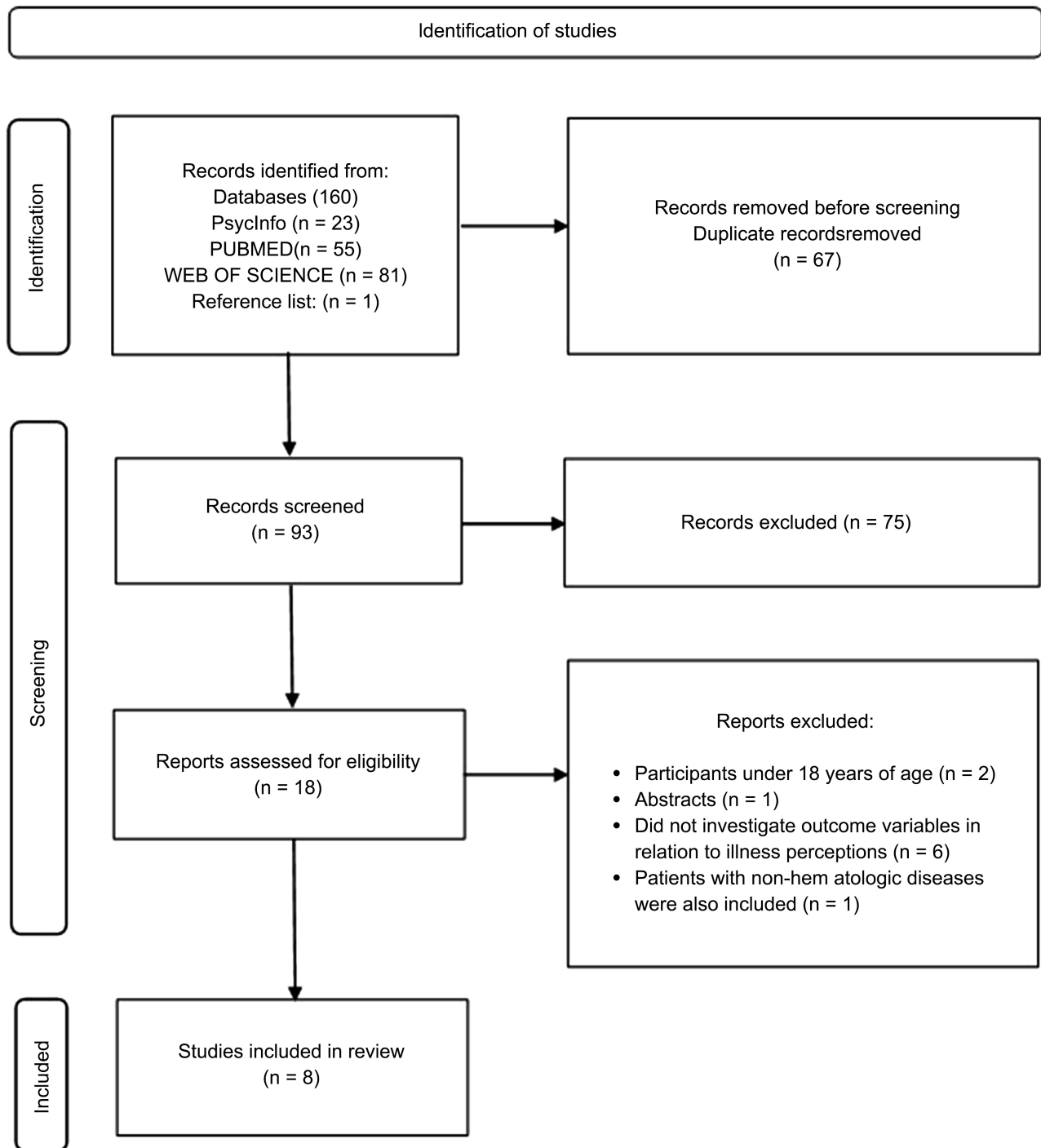
To maximize the yield of retrieved articles, the reference lists of the eligible papers and relevant reviews were also meticulously searched to include further studies reporting on illness perceptions and outcomes. The PRISMA flowchart (Page et al., 2021) illustrating the successive search steps for the selection of studies is presented in **Figure 2**.

### 2.2. Eligibility Criteria

The eligibility criteria were based on PICOS (Participants, Intervention, Comparison, Outcomes, Study design) acronym. The inclusion criteria were as follows: studies had to report only on adult ( $\geq 18$  years) patients, diagnosed with hematologic diseases. Articles had to be published in English in peer-reviewed journals and there were no restrictions on publication dates up to December 2023. Studies had to be quantitative, utilizing the IPQ, IPQ-R and B-IPQ questionnaires and providing data about the relationships among illness perceptions and illness outcomes within the context of Leventhal CSM. Studies were excluded if they included patients with non-hematologic diseases in their analyses, they included patients under the age of 18, they were qualitative and they were published as abstracts, theses, or conference proceedings.

### 2.3. Data Extraction

A data extraction form was designed using Excel, to obtain information from each study that has been included. Data were extracted from each study and included sample characteristics, study design, study country of origin, illness



**Figure 2.** Article selection process.

group-specific illness perceptions measured and study key points. Data were retrieved by the authors and consensus was ensured.

#### 2.4. Selection Process

The initial search identified 160 studies (23 from PsycInfo, 81 from Web of Science, 55 from PubMed and 1 from scanned reference lists), of which 67 dup-

licates were removed. Subsequently, 93 articles were screened based on titles, abstracts and keywords, leading to the exclusion of 75 studies that did not meet the inclusion criteria. Then, 18 articles underwent a full-text review, with 10 being excluded based on specific reasons. These exclusions included 2 studies involving participants under 18 years of age, 1 study abstract, 1 study including not only hematologic patients and 6 studies that did not investigate outcome variables in relation to illness perceptions. Ultimately, 8 studies (2030 subjects) were deemed suitable for inclusion in this review.

### 3. Results

#### 3.1. General Characteristics of the Studies

**Table 1** provides an overview of key study characteristics. As can be seen, studies included were conducted in various geographical regions, namely the USA (three studies) (Westbrook et al., 2016; Nelson et al., 2019; Arrato et al., 2022), Israel (one study) (Segal et al., 2021), Austria (one study) (Porkert et al., 2018), Portugal (one study) (Pinto et al., 2018), the Netherlands (one study) (Schoormans et al., 2020) and Belgium (one study) (Heyrman et al., 2023). Regarding the year of publication, one study was published in 2016 (Westbrook et al., 2016), two in 2018 (Pinto et al., 2018; Porkert et al., 2018), one in 2019 (Nelson et al., 2019), one in 2020 (Schoormans et al., 2020), one in 2021 (Segal et al., 2021), one in 2022 (Arrato et al., 2022) and one in 2023 (Heyrman et al., 2023). Those articles differed in terms of the type of the disorder: one study recruited patients with non-malignant hematologic disorders (hemophilia) (Pinto et al., 2018); five studies included patients with malignant hematologic disorders, namely chronic lymphocytic leukemia (two studies) (Westbrook et al., 2016; Arrato et al., 2022), cutaneous lymphomas (two studies) (Porkert et al., 2018; Segal et al., 2021); myelodysplastic syndromes (one study) (Heyrman et al., 2023), while patients in two studies had various hematologic malignancies (Nelson et al., 2019; Schoormans et al., 2020). Sample sizes varied, ranging from 30 to 993 participants. Gender distribution differed among studies, with one study including exclusively male participants (Pinto et al., 2018). Study designs also varied, including a randomized trial (Arrato et al., 2022), a prospective, longitudinal design (Nelson et al., 2019), a population-based registry study (Schoormans et al., 2020), a prospective observational study (Heyrman et al., 2023), while the remaining four were cross-sectional (Westbrook et al., 2016; Pinto et al., 2018; Porkert et al., 2018; Segal et al., 2021). To assess illness perceptions, four studies used the IPQ-R (Pinto et al., 2018; Porkert et al., 2018; Nelson et al., 2019; Segal et al., 2021) and four studies employed the B-IPQ (Westbrook et al., 2016; Schoormans et al., 2020; Arrato et al., 2022; Heyrman et al., 2023). Illness outcomes differed between articles, including HRQoL (Segal et al., 2021; Heyrman et al., 2023), psychological variables (Westbrook et al., 2016; Pinto et al., 2018; Nelson et al., 2019; Segal et al., 2021; Arrato et al., 2022) and fatigue (Westbrook et al., 2016; Schoormans et al., 2020).



**Table 1.** Summary of included articles: CLL: chronic lymphocytic leukemia, B-IPQ: Brief Illness Perceptions Questionnaire, CLs: Primary cutaneous lymphomas, IPQ-R: Revised Illness Perception Questionnaire, HRQoL: health-related quality of life, HSCT: hematopoietic stem cell transplantation, NHL: Non-Hodgkin's Lymphoma, HL: Hodgkin's Lymphoma, MF: Mycosis fungoides, QoL: quality of life, LPA: Latent Profile Analysis, MDS: myelodysplastic syndromes.

First author of the study, Year	Country	Total sample/ Males	Illness Group	Study Design	Illness Perceptions Tool	Key Findings
Westbrook et al., 2016	USA	N = 147 104 males	Relapsed/ Refractory CLL	Cross-Sectional	B-IPQ: Consequences, Timeline, Personal control, Treatment control, Identity, Coherence, Concern, Emotional representation	Consequences and emotional representations were positively associated with cancer-specific stress, depressive symptoms and fatigue. In addition, illness concern was positively associated with cancer-specific stress; identity was positively related to fatigue
Porket et al., 2018	Austria	N = 92 57 males	CLs	Cross-Sectional	IPQ-R: Identity, Consequences, Coherence, Personal control, Treatment control, Timeline acute/chronic, Timeline cyclical, Emotional representations, Causes	There was a significant association between illness perceptions and HRQoL
Pinto et al., 2018	Portugal	N = 102 All males	Hemophilia	Cross-Sectional	IPQ-R: Timeline acute/chronic, Timeline cyclical, Consequences, Personal control, Treatment control, Coherence, Emotional representation	Stronger perceptions about the consequences were significantly associated with higher depressive symptoms
Nelson et al., 2019	USA	N = 332 203 males	HSCT recipients (Leukemia, Lymphomas, Multiple Myeloma)	Prospective, longitudinal	IPQ-R: Timeline acute/chronic, Consequences, Personal control, Treatment control, Coherence	The illness course (more acute) and less severe consequences during the post-transplant period predicted improved psychological well-being and fewer psychological symptoms. Belief in better understanding and control (treatment or personal), during the post-transplant period, predicted better psychological well-being and less psychological symptoms



## Continued

Schoormans et al., 2020	Netherlands	N = 993 608 males	NHL, HL, CLL	Population-based registry	B-IPQ: Consequences, Timeline, Personal control, Treatment control, Identity, Concern, Coherence, Emotional representations	More negative perceptions of consequences, increased symptoms and lower illness coherence were associated with more fatigue
Segal et al., 2021	Israel	N = 30 25 males	MF (stage I)	Cross-Sectional	IPQ-R: Identity, Timeline-acute/chronic, Timeline cyclical, Consequences, Personal control, Treatment control, Coherence, Emotional representations, Causes	A positive correlation was found between illness coherence and QoL. Additionally, there was a negative association between illness coherence and depression
Arrato et al., 2022	USA	N = 259 171 males	CLL	Randomized Trial	B-IPQ: Consequences, Timeline, Personal control, Treatment control, Identity, Coherence, Concern, Emotional representation	The LPA representations predicted depressive symptoms, negative mood and cancer-specific stress after one year of continuous treatment
Heyrman et al., 2023	Belgium	N = 75 52 males	MDS	Prospective observational Trial	B-IPQ: Consequences, Timeline, Personal control, Treatment control, Identity, Coherence, Concern, Emotional representations, Causes	There was a strongly negative correlation between concerns and emotional perceptions and HRQOL. There was also a positive and significant relationship between treatment control and HRQOL

The above-mentioned studies have various limitations related to unbalanced group sizes that affect the accuracy of the statistical analysis (Pinto et al., 2018; Heyrman et al., 2023) and samples limited to a specific subset of patients, which raises questions about the generalizability of the results (Nelson et al., 2019; Segal et al., 2021; Arrato et al., 2022). In addition, the cross-sectional design of many of the articles does not allow for the establishment of temporal relationships between the variables studied (Westbrook et al., 2016; Pinto et al., 2018; Schoormans et al., 2020).

### 3.2. Illness Perceptions and Illness Outcomes

#### 3.2.1. Illness Perceptions and Psychological Outcomes

Several of the reviewed studies reported associations between illness perceptions and psychological outcomes, including depressive symptoms, anxiety, psychological well-being, cancer-specific stress and negative mood (Westbrook et al., 2016; Pinto et al., 2018; Nelson et al., 2019; Segal et al., 2021; Arrato et al., 2022).

Westbrook et al.'s (2016) study depicted the relationship between illness per-

ceptions and depressive symptoms, as well as cancer-specific stress, in a sample of 147 relapsed/refractory CLL patients from the USA. Primary analyses revealed that more negative consequences of illness and stronger emotional representations were associated with higher levels of depressive symptoms and cancer-specific stress. Furthermore, greater concern was linked to higher levels of cancer-specific stress in relapsed/refractory CLL patients. Multivariate regression analyses also showed that illness perceptions accounted for 25% of the variance in cancer-specific stress and 36% of the variance in depressive symptoms (Westbrook et al., 2016).

In a study of 102 Portuguese patients with hemophilia, Pinto et al. (2018) identified associations between illness perceptions, anxiety and depressive symptoms. Univariate analysis showed significant links between beliefs about the cyclical nature of the disease, negative consequences and stronger emotional representations with anxiety and depressive symptoms. Multivariate analysis indicated that stronger beliefs about the consequences of the disease were significantly associated with higher depressive symptoms (Pinto et al., 2018).

Nelson et al. (2019) conducted a longitudinal design study involving 332 patients with hematologic malignancies (leukemia, lymphoma and multiple myeloma) undergoing hematopoietic stem cell transplantation (HSCT). Researchers measured the extent to which illness perceptions, assessed before HSCT, predicted mental health outcomes, including depression, anxiety and psychological well-being up to 12 months post-HSCT. The authors found that patients' perceptions had a strong predictive value on mental health. More specifically, patients with a better understanding of their cancer, perceptions of less severe consequences and a belief in controlling their illness through treatment exhibited lower levels of anxiety and depression and higher levels of psychological well-being during their post-transplant recovery. Additionally, a stronger belief in personal control was associated with higher psychological well-being, while viewing the disease as more chronic was linked to higher levels of depression and lower psychological well-being (Nelson et al., 2019).

Segal et al. (2021) examined the relationship between illness perceptions and depression in 30 early-stage mycosis fungoides patients from Israel. Findings demonstrated a negative correlation between the perception of illness coherence and depression among the study participants. Additionally, the perception that the illness was triggered by psychological factors (stress and worry) was positively associated with anxiety and depression (Segal et al., 2021).

Arrato et al. (2022) used latent profile analysis (LPA) to identify distinct illness perception profiles, among a large sample ( $N = 259$ ) of individuals diagnosed with CLL. The analyses revealed three distinct patient groups characterized by varying degrees of illness perception: a low-impact group (low scores on identity, consequences and mild emotional representations), a moderate-impact group (moderate scores on identity, concerns, consequences and emotional influence) and a high impact group (high scores on the aforementioned dimen-

sions). These profiles significantly predicted psychological outcomes, including depressive symptoms, cancer-specific stress and negative mood, in patients undergoing 12 months of continuous treatment. More specifically, the low-impact group reported less depression, absence of negative mood and lower cancer-specific stress levels compared to the high-impact group (Arrato et al., 2022).

### 3.2.2. Illness Perceptions and Fatigue

In two studies, associations were observed between illness perceptions and levels of fatigue among patients with hematologic diseases (Westbrook et al., 2016; Schoormans et al., 2020). Westbrook et al. (2016) found that more negative consequences, stronger negative emotional representations and higher identity scores were linked to increased fatigue in patients with relapsed/refractory CLL. They also found that illness perceptions explained a substantial proportion (43%) of the variance in fatigue (Westbrook et al., 2016). In the study by Schoormans et al. (2020), illness perceptions, including consequences, identity and coherence, were linked to fatigue in a sample of 993 patients with various hematologic malignancies (HL, NHL and CLL), primarily NHL (N = 636). More negative perceptions of consequences, increased symptoms and lower illness coherence were associated with higher levels of fatigue. Additionally, in patients with CLL, a belief in illness control through treatment and, in NHL patients, lower illness coherence was significantly related to more fatigue (Schoormans et al., 2020).

### 3.2.3. Illness Perceptions and Quality of Life or Health-Related Quality of Life

In the study by Segal et al. (2021), the relationship between illness perceptions and quality of life (QoL) in patients with stage I mycosis fungoides was examined. Findings indicated a positive correlation between illness coherence and QoL. Conversely, QoL was negatively associated with consequences, emotional representations, identity and psychological causes such as stress and worry (Segal et al., 2021). Additionally, another study explored the link between illness perceptions and health-related quality of life (HRQoL) (Porkert et al., 2018), among 92 patients with primary cutaneous T- or B-cell lymphomas in Austria. This study found that there was a significant association between illness perceptions and HRQoL.

Furthermore, in the study by Heyrman et al. (2023), which investigated the relationship between illness perceptions and HRQoL in 75 patients suffering from myelodysplastic syndromes, the authors found that illness concerns were more strongly associated with HRQoL. More specifically, higher levels of concern were significantly associated with lower HRQoL. In addition, emotional representations also had a strong negative association with HRQoL. The same study provided evidence for a significant relationship between treatment control and HRQoL. In particular, a higher treatment control was linked with higher rates of HRQoL. Important correlations between HRQoL and consequences, identity and personal control were also reported: notably, lower personal control

was linked with lower scores of HRQoL. The authors also reported a negative correlation between symptoms and HRQoL and between as well consequences and HRQoL (Heyrman et al., 2023).

#### 4. Discussion

There is a significant body of research establishing associations between different aspects of the Common-Sense Model and illness outcomes in individuals with physical ailments. To the best of our knowledge, this narrative review is the first to examine the relationship between illness perceptions and illness outcomes in adult patients with hematologic disorders using this model as a framework. In this work, we conducted an extensive literature review, employing relevant textual terms associated with illness perceptions and hematologic diseases, across three electronic databases, with no limitations on publication dates through December 2023. Of note, the search strategy did not include any specific illness outcomes, thereby broadening the yield of retrieved articles.

The eight studies that met the inclusion criteria exhibited remarkable heterogeneity in terms of their objectives, study designs and the specific hematologic disorders under investigation. For instance, MF, CLL hemophilia and MDS have different impacts on patients depending on the stage and characteristics of the disease. Individuals with early-stage MF and CLL may have a relatively stable life expectancy and experience less discomfort; however, as MF advances, symptoms may worsen and more aggressive treatment may be required that can significantly impair the QoL, while the incurable nature of CLL results in unavoidable relapses and increasingly brief periods of remission (Westbrook et al., 2016; Segal et al., 2021). Hemophilia causes physical and psychological challenges that disrupt daily activities, due to pain, limited mobility, emotional upset, and social restrictions (Pinto et al., 2018). Meanwhile, the prognosis for MDS patients can vary widely, with those at high risk facing a markedly decreased life expectancy (Heyrman et al., 2023).

Despite the observed heterogeneity and the relatively limited number of included studies, all studies reported associations between illness perceptions and illness outcomes, such as HRQoL, fatigue and levels of anxiety and depression. Moreover, some studies showed that more negative illness perceptions, (e.g., heightened perceptions of consequences and intense emotional representations), were associated with inferior outcomes. These findings are consistent with the conclusions drawn from previous studies, which have reported that less favorable perceptions are correlated with poorer outcomes in patients with various acute and chronic diseases, including solid tumors (Hagger & Orbell, 2003; Broadbent et al., 2015; E. M. Richardson et al., 2017b; Luca et al., 2022). In particular, perceptions of severe consequences, chronicity of illness and a strong identity were positively related to illness outcomes such as psychological distress, but negatively correlated with outcomes such as psychological well-being, social functioning and vitality (Hagger & Orbell, 2003). In the same context, poor

quality of life, anxiety and depression were associated with a belief in higher consequences, stronger emotional representation, stronger identity and concern (Broadbent et al., 2015). It seems that patients, who think of their disease more negatively, may feel overwhelmed by its course, resulting in maladapting emotions such as anxiety and depression. On the other hand, research has shown that more favorable illness perceptions characterized for instance by an enhanced perception of control were significantly associated with better mental and physical health outcomes (Sawyer et al., 2019; Luca et al., 2022) and better quality of life (Broadbent et al., 2015). In patients with advanced, incurable illnesses, maintaining control over their active involvement in self-care is beneficial for their well-being and necessary for the preservation of their personal identity and dignity. Consequently, it seems reasonable that preserving a sense of control has been associated with better illness outcomes (e.g., good mental health), whereas an inadequate sense of control has been linked with negative outcomes (e.g., distress) (Rodríguez-Prat et al., 2022).

Furthermore, illness perceptions together with health literacy (Sørensen et al., 2012) have been associated with health-related quality of life, anxiety and depression in patients with coronary heart disease (Jennings et al., 2023) and intermittent claudication (Striberger et al., 2023). The role of health literacy in cancer has been explored (Holden et al., 2021), yet its mediating role between illness perceptions and quality of life, emotions and coping among patients with hematologic disorders, needs to be explored in future studies.

Apart from their role in predicting illness outcomes (Hagger & Orbell, 2003), illness perceptions have also been studied in terms of their involvement in patients' work participation (Hoving et al., 2010). More specifically, the belief that the disease is more controllable and more understandable was observed more often in employed patients. On the other hand, more negative illness perceptions such as a stronger illness identity and more negative emotional reactions were observed in non-working patients (Hoving et al., 2010). Work is a crucial component of quality of life (Tavakoli-Fard et al., 2016) and being able to continue working seems to be crucial for cancer patients (de Boer et al., 2008). In this perspective, illness perceptions are a valuable indicator of patients' ability to return to a type of normality and need to be considered for patients' empowerment initiatives. In addition, a rapidly growing body of studies has shown that illness perceptions have been associated with coping strategies and behaviors adopted by patients in order to manage their disease (Leventhal et al., 1980; Hagger & Orbell, 2003; French et al., 2006; Kucukarslan, 2012; Richardson et al., 2017b). Although the scope of this review is not to investigate interesting associations between illness perceptions and coping, some studies have provided evidence about the important role of the former in medication adherence among patients with hematologic disorders, such as hemophilia (Llewellyn et al., 2003; Lamiani et al., 2015; Torres-Ortuño et al., 2018) and sickle cell anemia (Atorkey et al., 2017; Badawy et al., 2017; Oudin-Dogliani et al., 2019).

This review is not without limitations. Even though the search did not contain any publication date limits, it is possible that relevant articles not indexed in databases searched or those in the grey literature may have been overlooked. Another limitation emerges from the fact that studies only published in English were reviewed. It is noteworthy that no formal quality assessment of the included studies was undertaken. Furthermore, some studies did not explore the longitudinal evolution of the relationships between illness perceptions and outcomes, not allowing definitive conclusions regarding the directionality of this. Finally, this review did not address the relationship between illness perceptions and specific coping strategies.

## 5. Future Directions

Several studies exist in the literature demonstrating that illness perceptions of patients with various disorders, including hematologic diseases, can be modified through various types of interventions such as providing information and education (Petrie et al., 2002; Moss-Morris et al., 2007; Broadbent et al., 2009; Husson et al., 2013; Richardson et al., 2017a; Hoefnagels et al., 2021; Nasimi et al., 2022). Research evidence suggests that interventions for illness perceptions have improved outcomes. For instance, patients with myocardial infarction were able to return to work sooner and felt more confident about being discharged from the hospital (Petrie et al., 2002). Furthermore, other studies showed that such interventions diminished the anxiety of the spouses of patients with myocardial infarction (Broadbent et al., 2009), enhanced mental and physical functioning in patients with chronic pain (Moss-Morris et al., 2007) and improved social aspects of HRQoL of individuals with head and neck cancer (Richardson et al., 2017a). For instance, identification of potentially negative illness perceptions, like illness consequences and emotional representations as well as their softening through interventions have been shown to be beneficial to outcomes (Moss-Morris et al., 2007). In accordance with these findings, the application of validated interventions aimed at modifying illness perceptions with the ultimate goal of improving outcomes, could be invaluable for patients with hematologic diseases.

## 6. Conclusion

The present study highlights the relationship between illness perceptions and illness outcomes across various hematologic patient populations and provides evidence that the poorer outcomes of patients are linked with negative illness beliefs. Additional studies are required to probe more deeply into the impact of illness perceptions in patients with hematologic disorders, in order to apply appropriate interventions that may lead to improved illness outcomes. Furthermore, future longitudinal research is required to strengthen the role of illness perceptions in disease outcomes in patients with hematologic disorders. Finally, future research should focus on specific and unique illness perceptions related to

individual hematologic disorders, given the different characteristics and features of these conditions.

### Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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