

## THE CROSS-CULTURAL DIFFERENCES IN SHAME AND GUILT AMONG INDIVIDUALS WITH CHRONIC DISEASES – A SCOPING REVIEW

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**Summary.** This scoping review delves into the emotional complexities faced by individuals with chronic diseases, focusing on shame and guilt across diverse cultural contexts. This literature overview underscores the significant role of shame and guilt in the lives of individuals with chronic diseases and emphasizes the necessity of expanding the understanding of culturally related shame and guilt concerning chronic diseases. Findings underscore the need for targeted interven-

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tions in the emotional landscape of chronic illnesses and cultural sensitivity while talking about chronic conditions.

**Key words:** shame, guilt, shame-proneness, guilt-proneness, chronic diseases, culture

Emotions are profoundly significant in human health and well-being (Vanderheiden & Mayer, 2017). According to researchers, basic emotions such as happiness, sadness, surprise, lust, and disgust are universally shared across cultures and linked to the physical survival of individuals. However, secondary or self-conscious emotions, including pride, shame, guilt, and embarrassment, are interconnected with specific cultures' values, morals, and anticipated behaviors, exhibiting substantial differences across societies (Yakeley, 2018). Furthermore, basic emotions are biologically driven and emerge within the first year of life, while self-conscious emotions develop later, beginning in the second year and continuing after that (Casimir & Schnegg, 2002; Yakeley, 2018). Thus, shame and guilt can be identified as negative social emotions particularly sensitive to culture.

The term "culture" refers to historically driven and socially transmitted things such as language, symbols, values, norms, rituals, laws, artifacts, and institutions (Tracy et al., 2007). Culture has a substantive influence on emotion, health, and well-being, as an individual's self is constructed by the culture (Kitayama & Park, 2007). For example, individuals in North American culture develop their "self" based on internal attributes such as abilities, talents, and personality traits. The culture's role is to facilitate the discovery, actualization, and confirmation of these internal attributes. Likewise, Western/individualistic cultures promote the "independent self". On the other hand, many Eastern/collectivist cultures introduced a set of different guidelines, beliefs, and norms; a major cultural task is to fit the individual's self into these norms. Hence, Eastern cultures promote the "interdependent self" (Kitayama et al., 2000). People in interdependent cultures define themselves in relation to others, while those in independent cultures do the opposite (Wong & Tsai, 2007).

Cultures may also be identified as guilt-based and shame-based cultures; using the criteria of internal and external sanctions (You, 1997). Based on this classification, Western/individualistic cultures are more integrated with guilt as these cultures are based on internalized value systems. On the other hand, Eastern/collectivist cultures are more integrated with shame, which is based on external social sanctions. Hence, individuals feeling shame are preoccupied with the way others are judging them, whereas individuals experiencing guilt are focused on the impact of their actions on others (Wolf et al., 2009).

The appropriateness of feeling certain emotions varies across cultures. Such variation exists due to the level of individualism and collectivism in particular cultures. For example, positive emotions such as pride and excitement are not highly encouraged in collectivistic cultures as those might detract the social harmony. On the other hand, in individualistic cultures, personal expression of positive emotions is very much

encouraged (Tov & Diener, 2013). Furthermore, cultural norms govern the expression of the way emotions are expressed and their intensity, impacting the overall well-being of society. This may explain why people from individualistic cultures report higher subjective well-being than individuals from collectivistic cultures (Diener & Lucas, 2004).

In both psychological and everyday contexts, people frequently use the terms shame and guilt interchangeably (Tangney, 1998; Wolf et al., 2009). Even though the term guilt and shame are confused as the same meaning in day-to-day language, they should not be understood as one homogeneous emotion (Cerna et al., 2022). The experiences of guilt and shame can be intertwined and distinct (Su & Hynie, 2019). Guilt can be identified as an awareness of having done something bad, committing a crime, or a feeling of responsibility for an offense whereas shame is a sense of inferiority or worthlessness. Therefore, guilt can be defined as “a negative, self-conscious, moral emotion which occurs when the individual admits that he has done something that transgresses a moral law. The focus is on inappropriate behavior”. (Vanderheiden & Mayer, 2017, p. 81). Conversely, shame can be defined as “a negative, self-conscious moral emotion which occurs when someone sees *his person* as being deficient because something he did transgress a moral law. The focus is on the person.” (Vanderheiden & Mayer, 2017, p. 81).

According to Su and Hynie (2019), experiencing guilt serves as a guide for healthier functioning of individuals in Western cultures, aiding in the strengthening of self-esteem, empathy, and perspective-taking. These adaptive functions, including coping with environmental challenges and prosocial behaviors such as helping others, are directly linked to the psychosocial well-being of individuals.

However, as Leith & Baumeister (1998) stated, shame is linked with personal distress and is harmful to human relationships because it arises as a result of real or imagined rejection from society. Hence, shame generates anger within an individual, and ultimately, it might cause internal blame, hostile criticism of others, insulting others, and withdrawal from social situations. Vanderheiden & Mayer (2017) also stated that shame is the affective component of subjective well-being, which produces negative affect. According to Crosskey et al. (2015), shame is associated with depression, alcohol and drug abuse, burnout, and self-rumination, whereas guilt is associated with social connectedness, hope, and empathy.

Nevertheless, according to You (1997) and Vanderheiden & Mayer (2017), shame can be identified as a valuable health resource. Shame motivates individuals to align themselves to connect with others. Shame acknowledges other people’s norms and expectations, highlights one’s own mistakes, and allows one to take steps to avoid repeating these mistakes in the future.

The emergence of a chronic illness marks a pivotal life event, indicating the commencement of what, for the majority, will be an enduring journey of adjusting to substantial alterations in physical, psychological, social, and environmental aspects. A wealth of research has shown that chronic illness significantly affects the mental, social, and physical well-being of patients (e.g., Trindade et al., 2018; Keles

et al., 2006; Megari, 2013). Those with chronic conditions often experience reduced feelings of self-reliance, weakened quality in social connections, a sense of being misunderstood, isolation and vulnerability, and even the perception of burdening others (Taylor, 2006).

## **Shame and Guilt in the Context of Chronic Diseases**

As previously indicated, shame is often seen as an uncomfortable emotion stemming from the perception that one's attributes are unfavorable. People facing chronic illnesses, especially those with evident symptoms or observable features, might theoretically be more prone to encountering feelings of shame (Trindade et al., 2016; Casati et al., 2000; Kellett & Gilbert, 2001). For example, individuals with inflammatory bowel disease (IBD) frequently communicate sensations of embarrassment, isolation, and diminished attractiveness due to the distinctive traits of the illness and its symptoms (Casati et al., 2000).

According to Dickerson et al. (2004), self-related emotions are directly linked with physiological processes. Specifically, prolonged exposure to evaluative and socially rejective conditions can trigger a cascade of physiological responses, including heightened cortisol levels and increased proinflammatory cytokine activity. These responses, in turn, contribute to the experience of shame and may ultimately lead to negative health outcomes (Dickerson et al., 2004). Moreover, some studies report the association of shame and guilt with chronic mental disorders. Exline et al. (2004) and Lee et al. (2001) have found a positive relationship between guilt and depression. Similarly, O'Connor et al. (2002) compared the self-focused motivations and other-focused motivations in submissive behavior and depression using depressive patients and students. The results revealed that depressed patients reached significantly higher scores in negative emotions, including guilt and fear, and lower scores in social comparison. The relationship between guilt and depression can be considered a special case, as highlighted by Cerna et al. (2022), who referenced the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). They noted that excessive and inappropriate guilt is specifically identified as one of the symptoms indicative of major depressive disorder.

Many patients have their own perceptions, knowledge, and understanding of the nature of their disease (Abrams & Finesinger, 1953). As previously explained, culture plays a significant role in shaping individual thinking patterns. When it comes to chronic diseases, individuals comprehend the diseases and related treatments in the light of cultural knowledge rather than medical knowledge. According to a study by Earnshaw & Quinn (2012), the stigma associated with healthcare workers and people with chronic diseases can have harmful effects on the quality of life of those with chronic diseases. Therefore, by reducing stereotyping, prejudice, and discrimination in healthcare settings and encouraging people with chronic diseases to mitigate anticipated stigma, their quality of life can be preserved.

However, to the best of our knowledge, there is a lack of research that has been focused on the effect of shame and guilt on individuals with chronic diseases across cultures. Therefore, the objective of this study is to review and synthesize existing literature on shame and guilt in the context of chronic diseases across different cultures.

## **Method**

The subsequent sections outline the procedures for acquiring the literature relevant to this review. The study applied a scoping review method. Contrary to systematic literature reviews (SLR), which address well-defined questions that often suggest the study design, a scoping literature review addresses broad questions and describes the literature widely, including diverse study methods and designs (Arksey & O'Malley, 2005). This approach fits the aim of our study due to the observational nature of the investigated studies that employ both qualitative and quantitative methods. Moreover, in the analyzed papers, a key variable – the culture, was often not considered/mentioned as the study variable but only sample characteristic. Therefore, applying the SLR method would lead to omitting some papers that described shame and guilt experienced by people with chronic conditions in many countries/ethnic groups but do not discuss the cultural context per se.

### **Search strategy – Initial Search**

The search strategy for this scoping review involved a three-stage approach targeting different databases and search phrases. A search of electronic databases (PubMed, Academic Search Complete, APA PsycArticles, and APA PsycInfo) was performed on September 14th, 2023. The search phrase was as follows: 'life-long' OR 'chronic' OR 'long-term' OR 'continuing' OR 'incurable disease' OR 'illness' OR 'condition' OR 'disorder' AND 'culture' OR 'cultural' OR 'culture-based' AND 'shame and guilt' OR 'shame-based' OR 'shame proneness'. Articles available from the inception date until 14 September 2023 were included.

This search generated an initial set of 63 papers, from which a screening process led to a final selection. Additionally, Google Scholar was utilized, but no new studies meeting the inclusion criteria were found.

### **Search strategy – Title and Abstract Screening**

After obtaining the initial yield of 63 papers, a review of the titles and abstracts was conducted. This phase involved assessing whether each was within the scope of the study. Due to the relatively low number of search results, the PI conducted screening by eye and then double-checked by another research team member. As a result of this step, 20 papers were selected for further evaluation.

## Search strategy – Detailed Paper Screening

The detailed screening process involved a thorough review of 20 articles. Each of these articles underwent meticulous scrutiny based on specific inclusion criteria, ensuring alignment with the study's focus. The refined inclusion and exclusion criteria are outlined below:

### *Inclusion criteria:*

- a. Individuals with chronic diseases participated in the study.
- b. Shame/ shame-proneness and/or guilt/ guilt-proneness were investigated within the study.
- c. Sample's ethnicity/nationality was stated, which allowed for categorizing the culture as collectivistic or individualistic culture.
- d. All observational empirical study designs, both qualitative and quantitative, were included (e.g., cohort studies, case-control studies, cross-sectional studies, and case studies).

### *Exclusion criteria.*

Papers were excluded for the following reasons:

- a. Full text in English could not be obtained.
- b. The source was a theoretical or a review article, with no primary or secondary data analyzed.
- c. The source was not peer-reviewed (book chapters, reports, theses/dissertations, conference proceedings).
- d. Studies where the participant's background is not clearly stated.
- e. Studies with heterogenous, culturally diverse participants analyzed jointly as one sample.
- f. Studies on people experiencing chronic symptoms (e.g., chronic pain), not chronic diseases.

## Study Categorization Process

Based on the ethnicity/nationality of study participants, the 20 selected studies were identified as either conducted within the shame-based culture (i.e., collectivistic culture) or guilt-based culture (i.e., individualistic culture). Subsequently, all 20 articles were further classified into five distinct categories based on the main focus of the study, namely: individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception in relation to chronic disease.

## Results

The detailed results of the review and characteristics of the analyzed studies are summarized in Table 1. Across the span of 69 years, 20 studies have investigated the experience of self-conscious emotions (shame and guilt) among people with

chronic diseases. The identified studies have been classified based on their main focus using qualitative assessment of the paper's content performed by two members of the research team. There were five established categories as follows: individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception in relation to chronic disease.

In the next step, within each category, the studies were divided based on the cultural setting. Thus, across all five categories, we distinguished studies performed within the individualistic culture, within the collectivistic culture, and studies comparing individualistic and collectivistic cultures.

### *Category 1 – Individual Experiences*

Seven studies that specifically delve into the experiences of individuals dealing with chronic diseases have been identified. These studies assess the cultural implications of chronic illnesses, particularly focusing on the emotions of shame and guilt. Five of these studies have been conducted with the participation of individuals living in individualistic cultures (Harrison et al., 2017; Furmańska et al., 2020; Ten Klooster et al., 2014; Robertson et al., 2021; Walker, 2017), while one study was conducted within a collectivistic culture (Taşkıntuna & Özçürümez, 2011). Additionally, one study, by El-Mansoury et al. (2008), examines a comparison between individualistic and collectivistic cultures.

Ten Klooster et al. (2014) studied feelings of guilt and shame in patients with rheumatoid arthritis (RA) in the individualistic culture of the Netherlands. This study aimed to investigate whether individuals diagnosed with rheumatoid arthritis (RA) tend to experience higher levels of general guilt and shame compared to those without RA. It involved 85 patients with rheumatoid arthritis and 59 individuals without RA. The most notable finding of this study was that patients with longstanding RA did not experience a greater general propensity for shame or guilt than their comparison group without RA. Furthermore, shame and guilt were only associated with the demographic and psychosocial characteristics of the patients and not with the clinical or physical aspects of the disease. The overall study results suggest that Dutch RA patients generally do not experience significant shame or guilt. According to the authors, several reasons might explain why shame and guilt were not notably higher in these patients. Firstly, RA is widely recognized as a medical condition by both doctors and the public. People seem to have realistic views about arthritis, understanding its seriousness and consequences and do not think patients can control the disease's course. This lack of stigma means RA patients likely do not feel the need to justify or hide their condition. Moreover, advances in understanding RA causes and effective treatments have made the disease milder compared to decades ago. RA patients today are generally less disabled, with fewer visible deformities or reliance on assistive devices. This contrasts with conditions like breast cancer, where visible signs may lead to bodily shame.

Table 1. Study characteristics and results

No.	Study	Aim	Country/ Ethnicity
01	ten Klooster, P.M., Christenhusz, L.C., Taal, E., Eggelmeijer, F., van Woerkom, J.-M., & Rasker, J.J. (2014). Feelings of guilt and shame in patients with rheumatoid arthritis. <i>Clinical Rheumatology</i> , 33(7), 903–910, doi: 10.1007/s10067-014-2516-3	The study aimed to determine whether individuals with rheumatoid arthritis (RA) experience higher levels of general guilt and shame in comparison to those without RA, and to explore potential factors associated with these emotions in the context of RA	Netherlands
02	Harrison, S.L., Robertson, N., Goldstein, R.S., & Brooks, D. (2017). Exploring self-conscious emotions in individuals with chronic obstructive pulmonary disease. <i>Chronic Respiratory Disease</i> , 14(1), 22–32, doi: 10.1177/1479972316654284	The study aimed to investigate the manifestation of self-conscious emotions, examine potential correlations with adverse health outcomes, and compare the expression of these emotions between individuals with chronic obstructive pulmonary disease (COPD) and a healthy control group.	Canada
03	Walker, L. (2017). ‘There’s no pill to help you deal with the guilt and shame’: Contemporary experiences of HIV in the United Kingdom. <i>Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine</i> , 23(1), 97–113, doi: 10.1177/1363459317739436	The main aim of the study was to understand the impact of receiving and adjusting to an HIV diagnosis in today’s UK society. Additionally, the study aimed to explore whether the social experiences of individuals living with HIV have changed or stayed consistent in response to biomedical advancements.	United Kingdom
04	Furmańska, J., Rzepa, T., Koziarska, D., Rutkowska, E., & Bulsa, M. (2020). Stereotypes vs. reality: Shame and coping strategies applied by healthy subjects and multiple sclerosis patients – preliminary research. <i>Postępy Psychiatrii i Neurologii</i> , 29(1), 11–24, doi: 10.5114/ppn.2020.94692	This study aimed to assess the degree of disease-related shame in individuals with multiple sclerosis (MS) in comparison to healthy individuals who identified with the stereotype of a chronic, incurable disease leading to disability.	Poland



Sample description	Methodology	Findings
<p>Study participants included 85 outpatients (77% females, median age 62 years, median disease duration 11 years). A peer control group of 59 individuals was age and sex-matched for comparative analysis.</p>	<p>quantitative, cross-sectional comparative study</p>	<p>Individuals with longstanding RA did not undergo heightened general feelings or susceptibility to shame or guilt in comparison to their peers without RA. Additionally, the occurrences of shame and guilt were solely linked to the demographic and psychosocial characteristics of the patients, and not to the clinical or physical aspects of the disease.</p>
<p>Study participants included 15 individuals with COPD who participated in interviews. The quantitative component involved 70 patients diagnosed with COPD and 61 healthy controls.</p>	<p>mixed-methods study</p>	<p>Five interview-derived themes were discerned: grief, a range of blame, concern regarding external perceptions, concealment, and future-related apprehension. Quantitative results showed that individuals with COPD expressed reduced self-compassion, heightened shame, and diminished pride compared to their healthy counterparts.</p>
<p>The study participants included individuals aged 18–35 years who had received a diagnosis of HIV within the past 5 years.</p>	<p>qualitative study (online survey structured around open-ended questions and two interviews)</p>	<p>The data revealed a mix of experiences and expectations, highlighting that while HIV is considered 'normal' in some aspects, there are still ongoing feelings of fear, shame, and stigma. This underscores its continued status as a highly 'socially impactful' disease.</p>
<p>The study participants included 60 individuals, comprising 30 patients diagnosed with MS and 30 healthy subjects.</p>	<p>quantitative, cross-sectional comparative study</p>	<p>The study findings indicated no significant difference in the levels of disease-related shame between individuals with MS and healthy subjects. Both groups exhibited similar use of coping strategies such as avoidance, self-blame, and blaming others. Notably, MS patients were less inclined to employ withdrawal as a coping strategy compared to the healthy group. Within the MS patient group, a positive correlation was observed between the level of disease-related shame and the utilization of withdrawal and self-blame as coping mechanisms.</p>

cont. table 1

No.	Study	Aim	Country/ Ethnicity
05	Robertson, N., Gunn, S., & Piper, R. (2021). The experience of self-conscious emotions in inflammatory bowel disease: A thematic analysis. <i>Journal of Clinical Psychology in Medical Settings</i> , 29(2), 344–356. doi: 10.1007/s10880-021-09778-0	The study aimed to explore the presence of self-conscious emotions in individuals with Inflammatory Bowel Disease (IBD).	United Kingdom
06	Taşkıntuna, N., & Özçürümez, G. (2011) End-stage renal disease and psychological trauma: Shame and guilt in hemodialysis patients, transplantation recipient and donor candidates, and controls. <i>Nöro Psikiyatri Arşivi</i> , 48(4), 249–254, doi: 10.4274/npa.y5846	The study aimed to investigate the impact of psychological trauma, specifically examining shame and guilt, on mood and health-related quality of life (HRQOL) among individuals with end-stage renal disease (ESRD).	Türkiye
07	Shahram, S.Z., Böttorff, J.L., Oelke, N.D., Kurtz, D.L., Thomas, V., Spittal, P.M., & and For the Cedar Project Partnership. (2017). Mapping the social determinants of substance use for pregnant-involved young Aboriginal women. <i>International Journal of Qualitative Studies on Health and Well-Being</i> , 12(1), 1275155, doi: 10.1080/17482631.2016.1275155	This study aimed to understand how young Indigenous women, engaged in pregnancy, conceptualize and grasp the interconnections of social determinants associated with substance use.	Canada
08	Lindqvist, G., & Hallberg, L.R.-M. (2010). 'Feelings of guilt due to self-inflicted disease.' <i>Journal of Health Psychology</i> , 15(3), 456–466, doi: 10.1177/1359105309353646	This study aimed to investigate the main challenges confronted by individuals living with chronic obstructive pulmonary disease (COPD) and explore their strategies for managing their daily lives.	Sweden
09	Mondia, S., Hichenberg, S., Kerr, E., Eisenberg, M., & Kissane, D.W. (2011). The impact of Asian American value systems on palliative care. <i>American Journal of Hospice and Palliative Medicine</i> , 29(6), 443–448, doi: 10.1177/1049909111426281	This study aimed to investigate the experiences of Asian American families in the context of palliative care, utilizing a cultural lens.	USA

Sample description	Methodology	Findings
The study included 15 participants from outpatient IBD clinics and patient groups.	qualitative study (semi-structured interviews)	The analysis identified themes that showed how people felt self-conscious emotions when their experiences threatened the identities they preferred.
The study participants included four groups: the hemodialysis group (56), the recipient candidate group (66), the donor candidate group (41), and 51 healthy individuals.	quantitative, cross-sectional comparative study	While the group differences for neither guilt nor shame reached statistical significance in the hemodialysis, recipient, and donor candidate groups, it was observed that hemodialysis patients exhibited the highest scores for depression, anxiety, and HRQOL.
The study participants included 17 young pregnant Indigenous women with experiences in substance use.	qualitative study (open-ended interviews)	Feelings of shame and guilt were strongly connected to low self-esteem, arising from the internalization of negative comments or behaviors from others, significantly affecting participants' emotional well-being.
The study participants included 23 individuals with COPD at different stages, from mild to severe.	qualitative study (interviews)	The study revealed a key theme focusing on feelings of guilt stemming from a self-inflicted illness due to smoking. This central aspect was connected to five coping strategies: making sense of existence, adapting to physical limitations, surrendering to fate, rationalizing the smoking-related cause, and ensuring adherence to daily medication.
The study involved 3 Asian American families.	qualitative study (case studies)	The themes identified from the interviews were encompassed family closeness, respect for hierarchy within the family, gender-defined roles, intergenerational tensions, preoccupation with shame, and limited emotional expressiveness.

cont. table 1

No.	Study	Aim	Country/ Ethnicity
10	Okazaki, S. (2000). Treatment delay among Asian-American patients with severe mental illness. <i>American Journal of Orthopsychiatry</i> , 70(1), 58–64, doi: 10.1037/h0087751	The study aimed to explore the degree of treatment delay and the factors linked to it among Asian-American patients seeking assistance for psychotic disorders at community outpatient mental health agencies.	USA
11	Abrams, R.D., & Finesinger, J.E. (1953). Guilt reactions in patients with cancer. <i>Cancer</i> , 6(3), 474–482, doi: 10.1002/1097-0142(195305)6:3<aid-cncr2820060305>3.0.co;2-p	The study aimed to evaluate the personality and emotional difficulties in cancer patients, shedding light on attitudes among patients and doctors.	USA
12	Cerna, A., Malinakova, K., Van Dijk, J.P., Zidkova, R., & Tavel, P. (2022). Guilt, shame and their associations with chronic diseases in Czech adults. <i>Psychology, Health &amp; Medicine</i> , 27(2), 503-512, doi: 10.1080/13548506.2021.1903058	This study aimed to explore the possible association between feelings of guilt and shame and physical health, particularly in the context of chronic diseases and selected conditions.	Czech Republic
13	Gilbert, P. (2000). The relationship of shame, social anxiety and depression: The role of the evaluation of social rank. <i>Clinical Psychology &amp; Psychotherapy</i> , 7(3), 174–189, doi: 10.1002/1099-0879(200007)7:3<174::AID-CPP236>3.0.CO;2-U	This study aimed to explore the links between shame, depression, and social anxiety using the social rank theory.	United Kingdom
14	Cantisano, N., Rimé, B., & Muñoz-Sastre, M.T. (2012). The social sharing of emotions in HIV/AIDS: A comparative study of HIV/AIDS, diabetic and cancer patients. <i>Journal of Health Psychology</i> , 18(10), 1255–1267, doi: 10.1177/1359105312462436	The study aimed to investigate variations in the social sharing of emotions among patients with HIV/AIDS, diabetes, and cancer.	Dominican Republic
15	Browne, J.L., Ventura, A., Mosely, K., & Speight, J. (2013). 'I call it the blame and shame disease': A qualitative study about perceptions of social stigma surrounding type 2 diabetes. <i>BMJ Open</i> , 3(11), doi: 10.1136/bmjopen-2013-003384	The study aimed to explore the social experiences of Australian adults dealing with type 2 diabetes mellitus (T2DM).	Australia

Sample description	Methodology	Findings
The study participants included a group of 62 Asian-American patients with psychotic disorders and 40 of their relatives.	mixed-methods study	In contrast to earlier observations of prolonged treatment delays in Asian Americans, this group demonstrated relatively low levels of stigma and shame. Extended treatment delays for patients were associated with elevated levels of shame and stigma experienced by their relatives.
The study included 60 participants with cancer.	qualitative study (interviews)	The study uncovered that patients' inclination to deny and avoid symptoms, hindering the pursuit of treatment, often stemmed from feelings of guilt.
The participants in the study comprised a nationally representative sample of 1000 Czech adults.	quantitative, cross-sectional correlational study	Respondents with elevated feelings of guilt, but not shame, were more prone to experiencing chronic diseases, including arthritis, back pain, cardiovascular disease, asthma, cancer, and depression or anxiety. The strongest association was observed in the case of cancer. No significant associations were found for diabetes and stroke, and feelings of shame were not correlated with chronic diseases.
The study included a group of 109 students and 50 individuals diagnosed with depression.	quantitative, cross-sectional correlational study	The results reveal a strong connection between shame, social anxiety, and depression (excluding guilt) with feelings of inferiority and submissive behavior.
The study participants included 35 HIV/AIDS outpatients, 35 diabetic outpatients, and 34 cancer outpatients.	quantitative, cross-sectional comparative study	The group with HIV/AIDS exhibited elevated levels of shame, guilt, and a reluctance to share illness-related emotions.
25 adults with T2DM were included as participants in the study.	qualitative study (interviews)	The study uncovered instances of social stigma experienced by individuals with T2DM.

cont. table 1

No.	Study	Aim	Country/ Ethnicity
16	Ho, L.P., & Goh, E.C. (2017). How HIV patients construct liveable identities in a shame based culture: The case of Singapore. <i>International Journal of Qualitative Studies on Health and Well-Being</i> , 12(1), 1333899, doi: 10.1080/17482631.2017.1333899	The study aimed to explore the process by which individuals diagnosed with HIV rebuild their identities after receiving the diagnosis.	Singapore
17	Dam, L., Cheng, A., Tran, P., Wong, S.S., Hershow, R., Cotler, S., & Cotler, S.J. (2016). Hepatitis B stigma and knowledge among Vietnamese in Ho Chi Minh City and Chicago. <i>Canadian Journal of Gastroenterology and Hepatology</i> , 2016, 1–8. doi: 10.1155/2016/1910292	The study aimed to define and contrast the comprehension and stigma linked to HBV within the Vietnamese communities in Ho Chi Minh City and Chicago. Simultaneously, it aimed to commence an evaluation of the cultural context surrounding HBV stigma.	Vietnamese people living in Ho Chi Minh City in Vietnam and Vietnamese people living in Chicago, USA
18	Walker, R.C., Walker, S., Morton, R.L., Tong, A., Howard, K., & Palmer, S.C. (2017). Māori patients' experiences and perspectives of chronic kidney disease: A New Zealand qualitative interview study. <i>BMJ Open</i> , 7(1), doi: 10.1136/bmjopen-2016-013829	The study aimed to uncover and articulate the experiences and viewpoints of Maori individuals living with chronic kidney disease.	New Zealand
19	Subandi, M.A., & Good, B.J. (2018). Shame as a cultural index of illness and recovery from psychotic illness in Java. <i>Asian Journal of Psychiatry</i> , 34, 33–37, doi: 10.1016/j.ajp.2018.04.005	The study aimed to explore the perceptions of shame in connection to psychotic illness among Javanese individuals.	Indonesia
20	El-Mansoury, T.M., Taal, E., Abdel-Nasser, A.M., Riemsma, R.P., Mahfouz, R., Mahmoud, J.A., El-Badawy, S.A., & Rasker, J.J. (2008). Loneliness among women with rheumatoid arthritis: A cross-cultural study in the Netherlands and Egypt. <i>Clinical Rheumatology</i> , 27(9), 1109–1118, doi: 10.1007/s10067-008-0876-2	The study aimed to explain loneliness as experienced by women with rheumatoid arthritis (RA) among Egyptian and Dutch female RA patients.	Egypt and the Netherlands

Sample description	Methodology	Findings
4 HIV patients (2 males and 2 females) participated in the study.	qualitative study (interviews)	The results revealed that even with the shift in the HIV trajectory from a terminal to a chronic condition, individuals living with HIV encounter challenges stemming from societal perceptions.
The sample included 842 participants from Ho Chi Minh City and 170 participants from Chicago.	quantitative, cross-sectional comparative study	Vietnamese residents in Chicago demonstrated heightened awareness of HBV but also exhibited higher stigma scores, including feelings of guilt and shame. Conversely, individuals in Ho Chi Minh City showed lower levels of HBV stigma.
The participants of this study included 13 Maori patients with CKD who were either nearing the need for dialysis or had started dialysis within the previous 12 months.	qualitative study (interviews)	The study uncovered that Maori concepts of whakama (disempowerment and embarrassment) and whakamana (enhanced self-esteem and self-determination) served as a comprehensive framework for interpreting the identified themes. These encompassed feeling disempowered by delayed CKD diagnosis, confronting the stigma of dialysis, developing and sustaining relationships to support treatment, and maintaining cultural identity.
The study included 6 psychotic patients and their family members as participants.	qualitative, ethnographic fieldwork	The data disclosed that participants utilized shame in three distinct ways. Firstly, it functioned as a cultural measure for illness and recovery; family members identified illness in the patient when a loss of shame was evident, and the return of shame was perceived as a sign of recovery. Secondly, shame was seen as a signal of relapse. Lastly, it was regarded as an obstacle to the recovery process.
The participants of this study included	quantitative, cross-sectional comparative study	The study found higher loneliness levels in Egyptian RA patients compared to Dutch. While low social support impacted loneliness in Dutch patients, it didn't in Egyptians. Egyptians also experienced more guilt about their condition than Dutch patients, despite similar pain and disability levels.

El-Mansoury et al. (2008) conducted a cross-cultural study comparing 36 Egyptian female RA patients with 140 female Dutch RA patients to explore loneliness within the context of rheumatoid arthritis (RA). The findings revealed that Egyptian patients reported higher levels of loneliness compared to their Dutch counterparts. Interestingly, while low social support was identified as a significant contributor to loneliness among Dutch RA patients, this association was not observed among Egyptian patients. Additionally, the study highlighted a comparison of RA patients in Egypt and the Netherlands, which found that Egyptian patients tended to experience greater feelings of guilt regarding their condition. Despite similar levels of pain and physical disability between the two countries, cultural influences, particularly feelings of guilt and shame, appeared to play a more prominent role in shaping the psychological experiences of RA patients in non-Western or developing nations.

Harrison et al. (2017) conducted a two-phase mixed-methods research endeavor to investigate the expression of self-conscious emotions, examining potential links to adverse health outcomes. The study aimed to compare these emotions between individuals with chronic obstructive pulmonary disease (COPD) and a control group of healthy individuals within a Canadian sample. The decision to choose questionnaires for assessing self-conscious emotions in individuals with COPD and healthy controls was guided by interviews conducted with 15 COPD participants. From these interviews, five main themes were identified: grief, a spectrum of blame, concern about the view of others, concealment, and worry about the future. Following this, the selected questionnaires were distributed to a total of 70 COPD patients and 61 healthy controls.

The qualitative results indicate that patients experience embarrassment due to concerns about how others perceive them. Consequently, individuals with COPD often worry about symptoms such as coughing and feel shame when coughing in front of others. In contrast, COPD patients described attempts to conceal their disability, often driven by guilt for contributing to their condition. According to the overall results of the study, COPD patients reported lower self-compassion, higher shame, and less pride than healthy controls.

Walker (2017) conducted a study on contemporary subjective experiences of people with HIV in the United Kingdom. This was a qualitative study that aimed to understand the experiences of being diagnosed and living with HIV. Furthermore, the author aimed to explore how the social experience of HIV changed in the light of biomedical development. A small-scale 40 online survey, structured around open-ended questions, was conducted alongside interviews with two individuals living with HIV who volunteered to participate. All participants had been diagnosed with HIV within the past five years. The analysis reveals three central themes: old narratives versus new knowledge; the experience of chronicity, manageability, and the impact of HIV on everyday life; and the societal perception of HIV as a 'social diagnosis,' including the pressures to normalize. The findings of the study revealed that there is a mixture of uncertain experiences and anticipated norms regarding people with HIV. Despite it



being a common health condition, there are still prevalent feelings of fear, shame, and stigma surrounding it, making it one of the most socially impactful diseases.

A comparative study on shame and coping strategies among individuals with multiple sclerosis (MS) and a control group was conducted in Poland by Furmańska et al. (2020). There were 60 people who participated in the study (30 patients with MS and 30 people in the control group). The study objective was to examine the extent of shame related to illness in individuals with MS compared to healthy individuals imagining themselves dealing with a chronic, incurable disease resulting in disability, a situation commonly perceived as challenging and exceptionally shameful. Additionally, the study aimed to assess the variations in coping strategies for shame between the two groups. The study found that both people with MS and the control group displayed similar levels of shame. Moreover, the coping strategies, including avoidance, self-blame, and blaming others, did not significantly differ between the groups. Although patients with MS were less inclined to use withdrawal as a coping mechanism compared to controls, their disease-related shame was linked to increased use of withdrawal and self-blame as strategies to cope with that shame.

Robertson et al. (2021) conducted a qualitative study investigating the experience of self-conscious emotions, including shame and embarrassment, among individuals with inflammatory bowel disease (IBD). Fifteen individuals with IBD were recruited from the clinic in the United Kingdom. The analysis of participant responses revealed two overarching themes, all centered around self-conscious emotions triggered by situations that challenged the participants' desired identities. The first theme, termed 'Lack of control,' highlighted the distress participants felt due to significant shifts in how they perceived themselves, and their efforts to regain a sense of stability in their identity. The second theme, named 'Lack of understanding,' encompassed the distress participants experienced when they became aware of being unfairly judged by others, adding to their emotional burden.

Taşkıntuna & Özçürümez (2011) conducted a study focused on end-stage renal disease (ESRD) and psychological trauma. This study was conducted in Turkey, a collectivistic country. There were four study groups: hemodialysis patients (56 individuals), transplantation recipients (66 individuals), donor candidates (41 individuals), and controls (51 individuals). The study aimed to assess whether the experience of shame and guilt has a negative effect on the mood and health-related quality of life among study groups. They hypothesized that individuals experiencing shame, stemming from negative self-evaluation, are likely to demonstrate higher scores in depression and anxiety, as well as lower health-related quality of life (HRQOL), compared to guilt, which is believed to result solely from a negative appraisal of one's behavior. However, according to the results of the study, hemodialysis patients reported higher depression, anxiety, and diminished HRQOL compared to the other three groups. However, there were no significant differences in shame and guilt. Interestingly, the control group in this study showed the highest shame scores. According to the author's interpretation of this result, the guilt and shame inventory (GSI) only assesses

the trait but not the state and it may not be appropriate in this kind of research. Furthermore, the Eastern culture-based self-consciousnesses is sensitive to seeing individuals confront hardships, such as organ loss and chronic diseases (Taşkıntuna & Özçürümez, 2011).

Summing up, the seven reviewed studies delve into the individual experiences of people with chronic diseases, particularly focusing on shame and guilt. Five studies were rooted in individualistic cultures. Among those, the Dutch study stood out by emphasizing the significance of demographic and psychological variables in assessing shame and guilt rather than disease-related factors, as the culture of the Netherlands is advanced in attitudes related to the longstanding RA. The cross-cultural study also underscored the significance of guilt and shame, which seemed to have a greater impact on shaping the psychological well-being of RA patients in non-Western or developing countries. Moreover, the Turkish study, representing a collectivistic culture, found no significant differences in shame and guilt scores among groups with end-stage renal disease but highlighted higher levels of depression, anxiety, and lower health-related quality of life in hemodialysis patients. This contrast underscores the need to understand cultural influences when examining emotions like shame and guilt in chronic illness contexts, offering valuable insights into both individualistic and collectivistic perspectives on coping with these emotions.

### *Category 2 – Risk Behaviors*

There were two qualitative studies focused on shame and guilt and their relationship to risk behaviors. One was conducted in individualistic Swedish culture, with the participation of people with COPD (Lindqvist & Hallberg, 2010). Another was conducted among pregnant-involved indigenous women of Canada who were using psychoactive substances (Shahram et al., 2017).

According to Shahram et al. (2017), seventeen young Indigenous pregnant-involved women (defined as those who have experienced pregnancy between the ages of 14 and 30) and who had experienced substance use throughout their lives, including during pregnancy, were eligible to participate in a mapping activity called CIRCLES (Charting Intersectional Relationships in the Context of Life Experiences with Substances). During this activity, the women created maps and discussed how various social determinants affected their experiences with pregnancy and substance use. The women identified 10 themes to express the factors influencing their substance use. These themes included traumatic life histories, socioeconomic status, culture, identity and spirituality, shame and guilt, mental wellness, family connections, romantic and platonic relationships, strength and hope, mothering, and the intersections of these determinants. According to the findings, low self-esteem was closely related to feelings of shame and guilt. These emotions stemmed from internalizing negative remarks or actions from others, significantly impacting their emotional well-being. Actively working to reverse these internalizations was crucial for their wellness. Feeling judged

or unwelcome were major barriers to accessing community support, and some women hesitated to seek treatment due to shame from past attempts or fear of failure.

In the Swedish study, the data were obtained through interviews with 23 individuals at different stages of COPD, ranging from mild to severe. The resulting substantive theory highlighted the central concern of experiencing guilt attributed to a self-inflicted disease related to smoking habits. This core category was associated with five managing strategies termed making sense of existence, adjusting to bodily restrictions, surrendering to fate, making excuses for the smoking-related cause, and creating compliance with daily medication. Accordingly, the guilt was related to the participants' awareness of the strong association between smoking behavior and COPD. Moreover, they blamed themselves for bringing the disease into their own lives.

In conclusion, both studies, conducted in individualistic Swedish culture and in collectivistic indigenous Canadian culture, illustrate a pattern where individuals internalize guilt-associated with risky behaviors like substance abuse or smoking. This internalization of guilt and self-blame appears to be a common trend in these individualistic cultures, significantly impacting individuals' emotional well-being and their approach to seeking support or treatment.

### *Category 3 – Patient care*

The literature review indicated three studies that were focused on patient care within the context of shame and guilt.

Mondia et al. (2011) conducted a qualitative exploration within the context of a randomized controlled trial focusing on family therapy initiated during palliative care and extending into bereavement. The study delved into the experiences of 3 Asian American families, aiming to understand the impact of the Asian American value system on palliative care dynamics. The findings revealed distinctive themes, including family closeness, respect for hierarchy within the family, gender-determined roles, intergenerational tensions, preoccupation with shame, and limited emotional expressiveness. These insights underscored the intricate nature of Asian American, collectivistic, cultural values. It emphasized the necessity for family therapists to thoughtfully consider and integrate these nuances into their approach, ensuring culturally sensitive care tailored to the unique needs of each family unit during palliative care and bereavement. Okazaki (2000) investigated treatment delay patterns in a less acculturated group of Asian Americans dealing with severe mental illness. In contrast to previous research, Okazaki's study discovered that these individuals and their families were thoughtful consumers of mental health services. However, the research revealed a paradoxical connection: higher levels of shame and stigma experienced by family members were associated with prolonged treatment delays for patients in a cohort of 62 Asian-American patients with severe mental illness and 40 of their relatives. This cohort reported relatively low levels of stigma and shame and a relatively short delay between the onset of psychiatric symptoms and the inception of treatment.

Additionally, Abrams & Finesinger's (1953) studied guilt reactions among cancer patients at Massachusetts General Hospital. The participants were a group of 60 patients with cancer. The study aimed to (1) assess the perspectives of both patients and their families regarding the diagnosis of a malignant tumor, (2) investigate how these attitudes impact the patients, and (3) propose a strategy for enhancing the care of individuals diagnosed with cancer. Their investigation revealed that patients' denial and avoidance of symptoms, significantly hindering treatment seeking, were often rooted in feelings of guilt.

Overall, these three studies underscore the imperative of recognizing culture-specific manifestations of guilt and shame in chronic diseases, particularly among diverse ethnic groups like Asian Americans. Understanding these cultural intricacies is crucial for tailoring healthcare interventions that effectively address emotional barriers and optimize treatment-seeking behavior among affected individuals and their families.

#### *Category 4 – Social attitudes/ stigma*

The literature review distinguished four works that described the effect of social attitudes/stigma related to chronic diseases. Two of them have been conducted in individualistic cultures (Browne et al., 2013; Cerna et al., 2022; Gilbert, 2000) and one in a collectivistic culture (Cantisano et al., 2012).

Cerna et al. (2022) conducted a study exploring the association between guilt and shame and chronic physical health conditions in Czech adults. The survey, which included 1000 participants, specifically examined eight selected chronic diseases: arthritis, asthma, back pain, cancer, cardiovascular disease, depression, diabetes, and stroke. The findings showed that feelings of guilt were associated with physical health, while feelings of shame were not. According to the authors, the impact of guilt on the quality of life of individuals with chronic diseases has been extensively explored in the literature. However, it is essential to recognize that guilt can also directly contribute to the onset and progression of the chronic disease. Therefore, it should be regarded as a significant subject within the clinical domain (Cerna et al., 2022).

Gilbert (2000) conducted a study in the UK that explored the associations between shame, depression, and social anxiety from the perspective of social rank theory. This theory argues that emotions and moods are significantly influenced by the perception of one's social status or rank. In this research, a group of 109 students and 50 individuals diagnosed with depression completed a set of self-report questionnaires specifically crafted to assess diverse facets of shame, guilt, pride, social anxiety, depression, and social rank (including self-perceptions of inferiority and submissive behavior). Results confirmed that shame, social anxiety, and depression (but not guilt) are highly related to feeling inferior and submissive behavior (Gilbert, 2000).

Cantisano et al. (2012) conducted a study in the collectivistic culture of the Dominican Republic to explore the nature of social emotion sharing among individuals living with HIV/AIDS. The study included 35 participants with HIV/AIDS, 35 with

diabetes, and 34 with cancer. According to the findings, the group of individuals with HIV/AIDS, comprising 35 participants, scored higher in shame, guilt, and reluctance to share emotions linked to their illness compared to individuals with diabetes or cancer. They also showed reduced instances of socially sharing these emotions and had fewer partners with whom they shared their feelings due to the nature of their chronic condition. The authors suggested that future research could focus on comparing how individuals living with HIV/AIDS are socially situated within individualistic and communal sociocultural settings.

A qualitative study (Browne et al., 2013) about perceptions of social stigma surrounding type 2 diabetes mellitus (T2DM) was conducted among individuals with T2DM living in Victoria State, Australia. The study included 25 participants who indicated that T2DM carried a social stigma or provided instances indicating the presence of such stigma. Key themes related to this stigma experience included feeling personally responsible for their condition and facing blame from others, encountering negative stereotypes, experiencing discrimination, and having limited life opportunities as a result.

These studies collectively demonstrate how individualistic and collectivistic cultural perspectives influence emotions like guilt, shame, and social stigma in the context of chronic diseases. Individualistic cultures emphasize personal responsibility and emotions' impact on health, while collectivistic cultures show how social attitudes and stigma affect individuals' experiences within the community.

### *Category 5 – Self-perception*

The literature review indicated four articles centered on how people with chronic illnesses perceive themselves and their condition within the context of their collectivistic cultural backgrounds.

Accordingly, Ho & Goh (2017) conducted qualitative research on how patients with HIV construct liveable identities in a shame-based culture in Singapore. They interviewed four patients with HIV (two males and two females) and uncovered that the evolution of HIV from a terminal to a chronic illness has not eased the challenges faced by those living with it, especially in Asian societies where there is significant fear and stigma surrounding HIV. People diagnosed with HIV often experience profound shame initially and must navigate this by reshaping their identities, containing that sense of shame, reinforcing their usual selves, and building new identities.

The comparative study conducted by Dam et al. (2016) sought to examine the levels of knowledge on hepatitis B virus (HBV) and the related stigma among 842 Vietnamese individuals residing in Ho Chi Minh City and 170 individuals in Chicago. The aim was to compare these two groups living in distinct cultural contexts and explore their understanding of HBV as well as the associated stigma within their respective communities. According to the findings, Vietnamese residents in Chicago showed greater awareness about how HBV spreads and its potential to cause chronic

infection and liver cancer. However, they also exhibited higher levels of stigma associated with HBV, feeling more guilt and shame about the disease and being more inclined to believe that those with HBV could harm others and should be isolated. In contrast, individuals in Ho Chi Minh City displayed lower levels of HBV stigma compared to Vietnamese living in Chicago, indicating shifting cultural attitudes in Vietnam. Authors claim that to combat HBV stigma, there's a need for culturally tailored educational campaigns.

Walker et al. (2017) looked into and described how Maori people, New Zealand's indigenous population, experience and perceive chronic kidney disease (CKD). This qualitative study aimed to uncover more about what CKD means for indigenous groups, which has not been widely studied before. Thirteen CKD patients who were near to or undergoing dialysis participated in interviews. Regret and self-blame, confronting the stigma of kidney disease, associated multigenerational fear, as well as shame and embarrassment were some of the themes identified in this study. Moreover, the authors have used two concepts of Maori, which are *whakama* (disempowerment and embarrassment) and *whakamana* (enhanced self-esteem and self-determination), as an overarching framework for interpreting the identified themes. The findings of the study highlighted that Maori individuals with CKD felt pushed to the sidelines in the New Zealand healthcare system because of late diagnoses. Moreover, problems such as the focus on individuals instead of families, longstanding concerns about dialysis across generations, and patient's belief that healthcare providers were not considering their cultural beliefs and values when making decisions, were identified.

An exploratory study was conducted on the complex Javanese meaning of shame in relation to psychotic disorders by Subandi & Good (2018). The study involved six individuals with psychosis and their families, and the research was carried out through ethnographic fieldwork conducted in Yogyakarta, Indonesia. The thematic analysis revealed that participants saw shame in three distinct ways. Initially, it served as a cultural measure for gauging illness and recovery; when someone lost their sense of shame, family members considered them ill, and the return of shame indicated recovery. Secondly, shame was seen as a sign of relapse. Lastly, it was perceived as an obstacle hindering the path to recovery.

The studies conducted by Ho & Goh (2017), Dam et al. (2016), Walker et al. (2017), and Subandi & Good (2018) provide nuanced insights into how individuals with chronic illnesses perceive their conditions within diverse cultural contexts. Ho & Goh's (2017) research on patients with HIV in Singapore illuminates the ongoing challenges faced by individuals with HIV, emphasizing the significant role of shame in shaping their identities in a culture marked by stigma. Dam et al.'s (2016) comparative study between Vietnamese communities in Ho Chi Minh City and Chicago highlights the differing levels of awareness and stigma associated with the hepatitis B virus, shedding light on cultural influences on disease perception. Walker et al.'s (2017) exploration of chronic kidney disease among Maori individuals in New Zealand unveils

themes of regret, shame, and systemic marginalization within the healthcare system, emphasizing the importance of cultural considerations in healthcare delivery. Finally, Subandi & Good's (2018) study on Javanese perspectives of shame regarding psychotic disorders demonstrates multifaceted cultural interpretations of shame as a gauge for illness, recovery, relapse, and as a barrier to recovery. Altogether, these studies underscore the intricate interplay between cultural backgrounds and self-perception of chronic illnesses, emphasizing the necessity of culturally sensitive approaches in healthcare as well as understanding and addressing the experiences of individuals living with chronic conditions. The studies also underscore the challenges of changing perceptions within collectivistic cultures and the importance of considering whole families and self-conscious emotions, like shame, in addressing chronic diseases within cultural contexts.

## Discussion

The scoping review of 19 papers highlights the significant role of cultural influences in shaping emotional responses to chronic diseases. More specifically, the effect of culture on individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception has been considered.

When considering the cultural influence of shame-proneness and guilt-proneness among individuals with chronic diseases, specific features associated with individualistic cultures have been identified. These include the influence of awareness (being educated of their disease, including its symptoms, treatments, and management strategies), personal and social factors (social support networks and personal beliefs) over clinical factors, access to advanced treatments, and the advantage of guilt over shame. Moreover, feelings of fear, shame, and stigma despite certain chronic diseases being common health conditions were noticed.

The influence of one's cultural background on the perception of chronic diseases seems to persist even after changing the place of residence. It is observed that individuals who have experienced stigma-associated diseases in their native culture may continue to experience heightened levels of guilt and/or shame in a host culture, even if the latter is perceived as more secure for them (Dam et al., 2016).

The studies conducted in the Netherlands by Tom Klooster et al. (2014), El-Mansoury et al. 2008) and Harrison et al. (2017) in Canada have underscored that shame and guilt related to chronic diseases are primarily linked to the psychosocial and demographic characteristics of individuals rather than solely to the clinical and physical aspects of the disease. Additionally, these studies have emphasized that advancements in treatments and increased societal awareness can contribute to reducing the stigma associated with chronic diseases. Consequently, tailored interventions considering these sociocultural nuances could potentially alleviate the emotional impact of chronic conditions. Nonetheless, individuals with chronic diseases tend to experience guilt more frequently than shame in individualistic societies (Cerna

et al., 2022; Abrams & Finesinger, 1953; Lindqvist & Hallberg, 2010), which is a finding supported by the research of You (1997) and Wolf et al. (2009).

According to Walker (2017) and Cantisano et al. (2012), individuals living with HIV/AIDS in the United Kingdom and the Dominican Republic, respectively, continue to experience shame and guilt and are often reluctant to share illness-related emotions due to the highly socially impactful nature of the disease, irrespective of the individualistic nature of the society. This underscores that certain chronic diseases remain deeply stigmatized regardless of the societal context, emphasizing the persistent challenges faced by individuals living with such conditions.

Moreover, the studies conducted by Okazaki (2000), Mondia et al. (2011), and Dam et al. (2016) draw attention to the influence of native culture over host culture in determining shame proneness and guilt proneness in chronic diseases. For instance, Okazaki (2000) and Mondia et al. (2011) found that Asian American families were preoccupied with shame, limited emotional expressiveness, and delays in seeking treatment for chronic diseases, regardless of their residence in individualistic societies. Furthermore, Dam et al. (2016) highlighted a higher sense of shame, guilt, and stigma experienced by Vietnamese people living in Chicago, USA, compared to those residing in Ho Chi Minh City, Vietnam specifically regarding HBV. These findings underscore the enduring impact of cultural norms and values on individuals' experiences of shame and guilt, regardless of their geographical location.

Considering the cultural influence of shame proneness and guilt proneness related to chronic diseases encountered by individuals in collectivistic cultures, it has been observed that individual well-being is determined by social perception, even though illness trajectories have improved positively over time. Specifically, Ho & Goh (2017) provided an example of the social challenges faced by individuals with HIV, notwithstanding medical advancements. Furthermore, some collectivistic cultures employ shame as a cultural index for chronic diseases. According to Subandi & Good (2018), shame has been identified as an indicator of recovery, relapse, and inhibitors to the recovery of psychotic illness. This research finding emphasizes the complex role of shame in chronic diseases within collectivistic cultures.

Moreover, in collectivist cultures, there tends to be a greater emphasis on interconnectedness and concern for others within the community. Therefore, individuals from these cultures may be more sensitive towards those dealing with chronic diseases or facing challenges such as the loss of an organ, potentially leading to heightened feelings of shame (Taşkıntuna & Özçürümez, 2011).

## **Clinical Implication**

Understanding the significant role of cultural influences in shaping emotional responses to chronic diseases has important implications for clinical practice. Healthcare professionals need to recognize the diverse cultural backgrounds of their patients and the impact that these cultural factors can have on the experiences of shame and guilt



related to living with chronic illnesses. Tailored interventions that take into account sociocultural nuances, such as awareness of cultural attitudes towards shame and guilt, can help mitigate the emotional impact of chronic conditions on patients. Additionally, increased societal awareness and advancements in treatments can contribute to reducing the stigma associated with chronic diseases. Clinicians should prioritize cultural competence and sensitivity in their approach to patient care, ensuring that individuals from all cultural backgrounds receive appropriate support and treatment for their chronic illnesses. By acknowledging and addressing the cultural dimensions of shame and guilt-proneness, healthcare providers can better support patients in coping with the emotional challenges of living with chronic diseases.

### **Study strengths**

The study excels in conducting a cross-cultural analysis of shame and guilt experiences among individuals with chronic diseases. It encompasses a diverse range of chronic conditions, providing a broad examination of shame and guilt. Utilizing a qualitative approach, the study deeply explores individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception. The current scoping review allowed to form clinical implications, emphasizing the need for culturally-tailored interventions.

Furthermore, the study highlights cultural nuances, recognizing the impact of individualistic values in societies like Canada and Sweden, as well as the role of collectivistic values in family-centered support. Despite cultural differences, the research identifies commonalities in emotional experiences, challenging the notion that cultural collectivism solely dictates responses in chronic diseases. The study also provides insights into societal attitudes, uncovering how broader cultural beliefs influence the emotional landscape of individuals with chronic diseases.

### **Limitations and future directions**

The current review had some limitations that need to be underlined. Firstly, our review was not a systematic literature review (SLR). Instead, we employed the scoping review method as it allowed us to include more studies than the SLR would include (Arksey & O'Malley, 2005). In 8 out of 19 reviewed studies culture was not one of the studied constructs, yet it was specified in the sample description (as ethnicity or nationality). Therefore, we could not put the results of the studies on chronic conditions and feelings of shame and guilt into specific cultural contexts. Although we employed a different methodological approach, we believe that it would be beneficial if future studies on feelings of shame and guilt among people with chronic conditions across various cultures could employ SLR.

Secondly, the reviewed studies' designs were cross-sectional. Therefore, inferring causality in studied relations is not possible. Thirdly, many of these studies were

conducted with a small number of participants; therefore, their results were underpowered. However, one should note that while studying chronic conditions it is often difficult or even impossible to reach a big sample (e.g., in case of rare genetic conditions). Fourthly, the analyzed studies concerned people with various chronic conditions; therefore, their results are characterized with low generalizability. Regardless of that, the review of these studies provides valuable information that may inspire future studies, foster the understanding of the emotional challenges of people with chronic conditions across cultures, and thus help in organizing culturally tailored patient care, support, and decreasing the disease-related stigma.

## Conclusion

The current literature review underscores the intricate interplay between cultural backgrounds, emotional experiences, and perceptions of chronic diseases. While individualistic cultures seem to influence the manifestation of self-conscious emotions, like shame and guilt, these responses are also shaped by demographic and psychosocial factors. In contrast, collectivistic cultures seem to exhibit more universal and deeply rooted perceptions influenced by familial and societal values.

The findings underscore the importance of tailoring interventions to accommodate cultural diversities, promoting comprehensive family-centered support within collectivistic cultures, and addressing nuanced emotional dynamics in individualistic societies. Recognizing these subtleties is crucial in fostering a more inclusive and empathetic environment for individuals with chronic diseases, transcending cultural barriers to provide holistic care and support.

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MIĘDZYKULTUROWE RÓŻNICE W ZAKRESIE  
PRZEŻYWANIA WSTYDU I POCZUCIA WINY  
PRZEZ OSOBY Z CHOROBYMI PRZEWLEKŁYMI –  
PRZEGLĄD ZAKRESU LITERATURY

**Streszczenie.** Niniejszy przegląd zakresu literatury zgłębia złożoność emocji, jakich doświadczają osoby z chorobami przewlekłymi, koncentrując się na wstydzie i poczuciu winy w różnych kontekstach kulturowych. Analiza literatury zwraca uwagę na ważną rolę jaką pełnią wstyd i poczucie winy w życiu osób z chorobami przewlekłymi oraz na konieczność zwiększania świadomości uwarunkowań kulturowych towarzyszących tym emocjom. Wyniki wskazują na konieczność tworzenia dopasowanych kulturowo interwencji oraz włączania wrażliwości kulturowej podczas rozważań na temat wstydu i poczucia winy w chorobach przewlekłych.

**Słowa kluczowe:** wstyd, poczucie winy, skłonność do przeżywania poczucia wstydu, skłonność do przeżywania poczucia winy, choroby przewlekłe, kultura

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