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Paediatric Perspectives in *The Truth According to Blue: Juvenile Fiction's Contributions to Patient-Centred Healthcare*

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Abstract: Convergence research is a remarkable and growing trend in the academic community that highlights the deep integration of knowledge, methodologies, and expertise across various fields. Medical humanities typifies this interdisciplinary union by synthesizing a range of disciplines such as humanities, social sciences, arts and medicine/healthcare. Through engagement with stories, novels, and essays to evaluate the human experience of illness, healing and care, medical humanities facilitate empathy and broaden the viewpoints of doctors and caregivers. This paper explores how this interdisciplinary framework of medical humanities aids the implementation of patient-centred care. The research is based on Eve Yohalem's middle-grade adventure novel *The Truth According to Blue* (2020). The novel revolves around the life of a thirteen-year-old protagonist who has Type 1 diabetes. Grounded in the life experiences of a paediatric patient, the study explores how the novel emphasizes the importance of recognising children's subjective experiences within clinical and caregiving circumstances. This study employs textual analysis as the primary method to examine language, themes, symbols, and pattern to discover implicit messages, biases, and social values in the text. Complementing textual analysis, discourse analysis is employed to analyse how illness, care and paediatric subjectivity are constructed in the novel. The analysis reveals that children's literature is a powerful tool for facilitating communication between children, parents and clinicians. This suggests an expanded scope of children's literature as a medium of expression for juvenile patients to validate their autonomy in a paternalistic model of healthcare where decision-making authority solely lies with doctors.

Keywords: *Convergence research, Health Humanities, Children's fiction, Patient-centred care*

Introduction

In recent years, the field of Health Humanities has gained growing attention for its significance in bridging the gap between medicine and various fields of arts and humanities. The flourishing field of Health Humanities uncovers the contemporary significance of humanistic scholarship and education (Contractor et. al. 303). With a purpose to foster humaneness, empathy, and wider perspectives in health practitioners, this transdisciplinary field of studies helps to reshapes the practice of medicine, healthcare and social care. Health Humanities as a field grants freedom to medical professionals to integrate their technical expertise with an extensive and human-centric healthcare paradigm. The focus is on interpersonal engagement and creative expression. Hence, the synthesis of Humanities in Health refers to diverse forms of human inquiry that enable us to improve our comprehension about human condition in health and in illness.

An important concept in Health Humanities is patient-centred care. As discussed by Abid et.al., by giving more importance to the patient's viewpoints, patient-centred care provides a personalised model of treatment style (144). It promotes the role of the patient from a mere receiver of impersonal care as in a 'physician centred' care model to a more active participant in the healing process. Mrs. Rohini Adepwar in her article *Patient-Centred Care: Key to Better Health Outcomes* explains the salient features of patient-centred care are treating patients with respect, ensuring transparent communication between medical practitioners and patients, offering emotional support, facilitating holistic care, recognising the involvement of family and friends, and guaranteeing easy access to care. In this model, more emphasise is given to individual health outcomes rather than population health outcomes. Thus, patient-centred care validates an active partnership between patients and clinicians.

As noted by Pulimeno et.al., juvenile literature has a remarkable function in facilitating patient-centred care. Children's literature is an influential tool that can be used to promote patient-centred care (13). There are studies that showcases that juvenile fiction holds the capacity to be utilised as a medium to strengthen health literacy among children. In many children's stories, health-related challenges are delicately blended, either directly or indirectly. A growing number of such works can provide information regarding various topics including illness, disease, recovery and healthcare. The majority of stories that deal with illness highlight the systemic issues of the setting to which they belong. For children, these books serve as a pedagogic tool that helps in deconstructing complex health concepts. They help to teach and reinforce health concepts and skills. Whereas for medical professionals, children's literature enhances narrative competence and compassion.

The aim of this article is to examine how juvenile fiction contributes to the principles of patient-centred care. The American author Eve Yohalem's 2020 children's adventure novel *The Truth According to Blue* functions as the primary text for the study. The story revolves around a thirteen-

year-old girl named Blue Brion. Though the novel is mostly renowned for its central plot related to the protagonist's hunt for a legendary ship of gold, the close reading of the text exposes the day-to-day struggles of a young child who is type 1 Diabetic. By centring on this perspective of the book, the present study analyses how the novel portrays the experience of living with a chronic illness from a paediatric outlook. Also, the paper attempts to explore how the key principles of patient-centred care, including empathy, agency and the child's voice are reflected in the narrative. Finally, the article demonstrates the scope of children's literature within the interdisciplinary field of health humanities.

Children's Literature as a Legitimate Form of Illness Fiction

Neil Vickers, in his book titled *A History of English Autobiographies* describes about the evolution of illness narratives in English literature. Illness narratives encompass fictional and non-fictional works that describes the experiences of disease and illness (388). They often discuss the themes of pain, suffering, identity, and care. Illness narratives are beneficial for both the patients as well as the caregivers. Essentially, these accounts impart understanding for healthcare providers into not only the patient's disease but also on their social and emotional well-being. At the same time, they are also written in the carers' point of view. A significant proportion of the works that fall under this genre are written as a mechanism of coping with harsh realities of life.

The origin of illness narratives can be traced back to personal diaries, letters and memoirs. Personal diaries of Lady Anne Clifford, Elizabeth Freke, etc. are examples of such works. These writings documented the viability, pain and financial constraints of illness during 1600s and 1700s. Early eighteenth century witnessed the emergence of fictionalised accounts in this category especially through *A Journal of the Plague Year* (1722) by Daniel Defoe, a fictionalised account of the 1665 plague. Later on, illness became a frequently used theme in many of the nineteenth century Victorian novels that explored its social and communal consequences.

The emergence of paediatric illness narratives has become a major turning point in healthcare academia. They act as an anchor in elevating the comprehension of children's experience of illness among medical practitioners. By discussing the disintegration of life after the diagnosis, fear of death and confusion about identity among the diseased children, these narratives play a pivotal role in generating unique insights for physicians. They have become a catalyst for reforming the entire approach of treatment into a more ethical and empathetic model. The feelings of young patients are strongly amplified in these narratives and have become a direction modifier in the field of medical education to such an extent that medical curricula have started including them.

The Truth According to Blue is one of the best instances of juvenile fiction that can be taken into account as a valid form of illness narrative. It discusses the emotional and psychological dimension of the young narrator. The most common key feature of illness narratives is the exploration

of identity disruption, which is a byproduct of chronic illness. This breakdown of identity often causes existential crisis in those who are diseased. According to Michael Bury such illness makes a person to reconsider who they are and what is the meaning of their life is (169). In the novel, there is an explicit discussion of how Type 1 diabetes consumes Blue's sense of self. Her entire existence is shrunk down into just a 'Diabetes girl'. In her adolescence, when most individuals form a strong base of their self, her identity is destabilised due to the disease. She even risks her life to establish herself beyond her illness. "I want to find one of the most famous missing treasures in the world. I'm so sick of the biggest thing in my life being my stupid blood sugar. There has to be something more to me than that!" (Yohalem 189). Blue's actions to reclaim an identity beyond her disease exposes the emotional burdens of chronically ill individuals.

Representations of paediatric subjectivity in the text

Paediatric subjectivity is a central concern of various fields such as medical humanities, childhood studies, paediatric psychology, developmental psychology, bioethics, paediatric medicine, disability studies etc. The term paediatric subjectivity relates to how children evolve their own personal, internal and emotional interpretation of the world. This development occurs during a period from infancy to adolescence. The discrimination of children's experience from those of adults is one of the major events in this growth period leading to paediatric subjectivity. In a way paediatric subjectivity is an acceptance to a child's individual experiences, feelings and viewpoints. Beyond just objects of care, paediatric subjectivity acknowledges children as agents with their own authority and opinions. Important factors that mould this kind of subjectivity are intellectual development, interpersonal relations and culture. It is also influenced by the concept of "subjective wellbeing" which "refers to how people *experience* and *evaluate* their lives and specific domains and activities in their lives" (Stone and Mackie 1). In this way, the concept of paediatric subjectivity underlines the scope of validating children's participation in interpreting their own experiences.

Eve Yohalem presents Blue Breon not as an object of clinical communication but as an explicator of the particular disease. Many terms related to the illness naturally flow into her day-to-day dialogues, showcasing that she is not a passive participant in her journey of fighting the disease. "By the time I finished testing my blood sugar and entering the number of carbs I was about to eat into my pump so it would know how much insulin to give me" (11). Many instances in the story tries to establish the chronic condition as nothing abnormal but persistent. The inclusion of the medical condition as one among many threads such as friendship, treasure hunt and family can be read as a deliberate attempt from the part of the author to resist pathologizing the child. Thus, the novel through its storyline portrays the capability of children to be active managers of their clinical condition, by affirming their agency.

At the same time, through Blue's first-person narration of her lived experience of Type 1 diabetes, the work exposes the issues of identity conflict, violation of her autonomy and emotional distress inflicted upon her by the society. While she extraordinarily manages her illness on her own, unnecessary interventions and comments from the people around her constantly reminds her of her illness. In the initial chapters of the novel, the resentment of Blue to become a poster child at the diabetes fundraiser is explained. This is a critique against all the commodification of illness led by adults either knowingly or unknowingly. Even the acts performed by her parents, though out of care, are felt as an abrasion of her privacy. The novel also criticises the judgemental attitude of the society about the illness that arise out of their misconceptions. These misunderstandings and prejudices question Blue's autonomy as an individual with many dreams and aspirations. "Lots of people think you get diabetes because you eat too much sugar or you don't exercise, and if you just lose weight and choke down a bottle of cinnamon every day, it'll go away. Lots of people are wrong." (17). Consequently, the novel critiques the societal misconceptions and attitudes toward illness diminish the agency of children who are chronically diseased.

Reflections of emotional and social dimensions of illness

In the article *Emotional Dimensions of Illness*, Turner and Kelly emphasise the significance of emotional well-being of a patient during their battle with the disease. "Although adherence to prescribed treatments may improve the course of a disease, the clinician cannot promise the patient that "being good" will be rewarded; in some diseases, such as diabetes, impairment may still occur" (126). The emotional dimension of health comprises a person's emotional status and mood. It is immediately connected with one's sense of self and determines one's capacity to control and manage his/her emotions. Other key dimensions of health, like physical, social, intellectual, and spiritual are affected in relation to emotional health. It is also closely associated with the mental health. Medical illness adversely effects on mental well-being and may create emotional problems.

Meanwhile, "social determinants of health – broadly defined by the World Health Organisation as the conditions in which people are born, grow, live, work and age, and people's access to power, money and resources – have a powerful influence on health inequities". A positive material environment and a positive human environment are two components that make a strong foundation for good social health. In context of illness, this dimension includes the social, economic, cultural and behavioural factors. These factors can influence the experience of illness, its management, and distribution across populations. Disease is mainly regarded as a biological malfunction. At the same time, illness is considered as the personal and social experience of the sufferer. Environment and culture can affect such experiences of the sick person. Even in many cases, the society acts as the interpreter of symptoms and determiner of whether a condition is considered as illness.

The frustration, identity crisis, and indignation expressed by Blue at many occasions in the novel demonstrate her emotional state, which is tired of proving herself to be an individual whose existence extends more than her illness. On a number of occasions, Eve Yohalem, through her character, illustrates the emotional dimension of being ill. The novel is a testament to how a chronic illness can generate existential anxiety and in turn contribute to creating quiet and continuous psychological stress to the protagonist: “I’d stay awake half the night worrying about how there was no cure for diabetes, which meant that I was going to have this disease for the rest of my life” (23). In the classroom scene presented in the story, the central character feels ashamed and embarrassed when her disease was exposed resulting in the degradation of her self-esteem and self-confidence. “I got lighter and lighter and lighter until I floated from the floor to the ceiling. My body became paper-thin and see-through...” (29). This moment illustrates the emotional vulnerability experienced by young patients when their disease gets publicly revealed.

The author also exposes the general misconceptions and stereotypes related to illness. Blue finds it difficult when it becomes a constant effort to clarify unwanted doubts raised by the people around her. Their never-ending curiosity regarding the disease and their unsolicited sympathies make her feel suffocated and disturbed. It becomes her duty, though imposed, to educate this ignorant section of the society, to protect her autonomy. “Jules, who thinks diabetes is “a thing that happens to fat people,” was making me feel like an idiot” (47). Characters like Jules, her father, etc., are a microcosm of a society who are unaware of and spreads misinformation and stereotypes related to this illness. The novel also discusses the economic aspect of the disease. By portraying a family that sells their valuable assets such as the gold coin, and their unstable business etc, the novel points out the financial burden exerted upon the patient and the caregivers, especially in managing a chronic illness. “Diabetes is expensive,” I said at last. They weren’t the words I was trying to say, but they were true. My insulin costs almost \$1,200 a month. Insurance covers a lot, but it doesn’t cover everything. Not even close” (188). These words reverberate her emotional state of helplessness and grief, highlighting the psychological stress induced by the economic burdens of treatment on the patients.

Patient-centred care model illustrated in the narrative

The Truth According to Blue is an ideal example of a narrative that can support modern treatment and care goals. *The State of Person-Centred Care 2025 Report* by Picker Healthcare, an international charity and non-profit organisation, proposes eight principles of patient-centred care (12-27). Blue’s life - her needs, frustrations and demands - all align with each of these principles. Through different events happening in the life of Blue, the novelist reiterates the need for and importance of patient-centred care.

Blue constantly urges for recognising her individuality, autonomy, and dignity. She wants to be treated like any other girl of her age, other than just a poster child or a symbol of inspiration or a medical case study: “I was so sick of being the sick girl” (144). The respect she seeks for her values, choices, and needs is one of the core principles of patient-centred care. Similarly, this model of care also emphasizes the proper integration of care. In the novel, Blue’s life experiences showcase the level of emotional vulnerability of diseased persons; their anxieties and emotional fatigue. “The only thing scarier to me than managing my diabetes myself is not knowing how to manage my diabetes myself” (71). The novel calls for a coordinated method of care from doctors, allied medical professionals and her own family.

The patient-centred treatment style also gives importance to effective communication between doctors and patients. It insists on proper information exchange and education regarding the patient’s condition. This is because inaccurate knowledge can impose unwanted control and strain upon the patients. Blue manages most of her medications in the novel since she has received proper information about the disease. At the same time, the novel also gives examples of people who possess false awareness of the illness and making Blue’s life more complicated. “Jules!” Ed said. “Blue has diabetes, remember? She doesn’t eat candy.” Actually, I eat candy every day, but I didn’t think Mom would want me to give Ed a blood sugar management lesson two minutes after saying hello” (17). This principle underlines the fact that it is not the duty of patients to clarify all the baseless doubts and opinions of the public. The physical comfort of patients is also an important aspect of the patient-centred care. Chronic illness is not about random or episodic pain. It is a regular peace-making with one’s own body. The efforts a diseased individual has to invest to find physical comfort is vital because it is directly linked with their emotional well-being. The daily endeavours of Blue to manage her body depicted in the novel convey the importance of being physically fit and comfortable. “I check my blood sugar as soon as I get up in the morning, before and after I eat, before I go to bed, and once in the middle of the night — plus, I do it whenever Otis alerts me” (74). The patient’s self-reliance against the society’s anxieties about her medications is manifested here.

Patient-centred care also highlights the need to impart emotional support to patients. Also, it points out the benefits of healthy connection of friends and family. The lack of emotional support may escalate the anxiety levels of patients. In the novel, Blue experiences different dimensions of anxiety: anxiety about exposure, being judged, the financial expenses of the disease and existence (Crane et.al. 1096). This shows the necessity of psychological support to patients. “So, yeah, I could’ve died last night. I could die pretty much every night!” (104). There is a dual depiction of Blue’s family in the story. They are represented as a strong support for her in the majority of events. The financial sacrifices they make, the accompaniment they offer to fight all the prejudices and stereotypes show how supportive they are. But at the same time, they are also shown as overprotective. This destroys her

autonomy and privacy and causes tension within her. “You’re not like other kids. You have to be more careful.” I wished Dad had punched me in the stomach. I wished the roof had collapsed on my head. I wished I had fallen down the stairs and broken my leg in three places with the bone sticking out. Because any of those things would have hurt less than what Dad had just said” (172). Thus, the novel clearly portrays the complex role of family in providing care and support to patients without breaking their autonomy.

Another important principle of patient-centred care is the capability of patients to care for themselves. Illnesses, especially when they are chronic, requires continuous and consistent treatment. As evident in the novel, life time management is vital for Blue’s health condition. Patients like her are in need of constant support because the lack of such care can even cost their lives. Blue says: “If my blood sugar went too high I could go into ketoacidosis, which is medicalese for feeling like your brain has the stomach flu. And if it went too low I could pass out. Or worse (71)”. Thus, self-monitoring is of utmost importance in this scenario. The eighth and final principle of patient-centred care is access to care. Since huge financial expenditure is required for treatments, healthcare is not easily accessible to many even today. In the case of chronic conditions, this is even worse. One of the motives for Blue to find the treasure amidst her health condition, risking her life, is to find an alternative means of meeting her financial expenses since “Diabetes isn’t cheap” (35). This directly exposes the financial constraints, insurance barriers and structural inequalities that one should face during their course of treatment.

Children’s fiction as a valuable tool in Health Humanities

Children’s bodies have always been a site of monitoring, training and ethical moulding. For a long time, various kinds of juvenile fiction have also been used to serve this purpose. The increased use of children’s literature helps children understand illness better and also enables them to utilise this medium to express their voice and needs. This is applicable in the case of illness narratives also. In his study on the connection between medical field and children’s literature, Nasikah Ahmed argues that children’s book can assist its readers in coping with illness. “Children’s books have the potential to help young readers navigate medical diagnoses, reduce fear and anxiety when facing challenging decisions, and promote empathy and understanding” (4). Hence, Juvenile literature plays a crucial role in imparting awareness, empathy and understanding of illness among young readers.

In health humanities, narrative is fundamental in understanding illness. Children’s literature can actively contribute to this field mainly in three ways. Firstly, it can present medical knowledge in a simpler and more accessible form. Secondly, it reduces illness related anxiety. Finally, it helps to reflect lived experience, which is equally relevant to clinical knowledge. For example, in Blue’s story, complex medical terms and the daily routine of a Type 1 diabetic child are explained in a lucid manner

by blending them into the narrative. It can help young readers gain awareness of such a chronic disease that generally affect children, build empathy and encourage access to better healthcare.

Empathy and ethical formation constitute another focus of health humanities. Children's literature can aid this purpose of the field. This can be linked to the practice of reading out fables with moral lessons to children. Ahmed also opines that children's literature has an important educational and moral role of children's literature during a child's development. "Many believe children's books can include moral, ethical, and societal messages because they play an important role in helping children develop their moral compass, a sense of responsibility towards their community, and an understanding of the world around them" (61). The character named Jules in the novel, who accompanies Blue in the treasure hunt, undergoes a transformation. In the initial chapters, she is presented as someone who has little knowledge of Blue's condition and is merely sympathetic. Later, towards the end, she becomes compassionate and empathetic. This ability of children's literature to cultivate moral reasoning, empathy, and ethical imagination is highly valuable in health humanities scholarship. They can introduce various illnesses to children, the vulnerability they cause and the scope of care to young readers. Through such types of works, these readers can be shaped into ethically responsible citizens and healthcare professionals.

A great deal of work that falls under the genre of children's illness narratives, functions as a worthy medium for forming a language for illness. It acts as a platform not only for self-articulation but also as an assurance for the validation of emotional responses. For children with similar diseases, such literary works provide recognition and solidarity. Health humanities always uphold the necessity of companionship because isolation intensifies suffering. Narratives like that of Blue demonstrate that empowerment is attainable for everyone, including the chronically ill. Blue remarkably balances every aspect of her life. She is socially visible and lives as a regular child while being medically different. Thus, the field of health humanities may make use of these works to set models for young readers.

Implications of the study

The analysis of *The Truth According to Blue* exemplifies that children's literature can effectively communicate complex experiences of chronic illnesses with emotional and psychological depth. The novel presents Type 1 diabetes as a lived experience, demonstrating the disruption of identity, emotional contradictions and the social dimensions of illness. Thus, the study institutes juvenile fiction as a recognised and worthy form of an illness narrative within health humanities scholarship. This may result in the expansion of the health humanities database to include paediatric illness narratives, attributing them a serious treatment beyond their contemporary acknowledgement as peripheral or pedagogical texts. Such elevation of children's literature can encourage further interdisciplinary research into juvenile fiction as a significant contributor to medical discourse.

A further implication of the study is the benefit of incorporating children's literature in medical education. This can reform the curricula, especially in paediatrics and chronic care education. Medical textbooks can only explain the disease physiologically. But literary works can enlighten what it feels like to have it. Medical students are able to gain different insights into the emotional realm of having a disease by reading this kind of works, especially angst of long-term complications, the fear about social exposure and the disappointment of being reduced to a diagnosis. Chronicles like that of Blue strengthen diagnostic empathy in medical professionals. They may get trained to recognise the invisible emotional suffering of individuals with chronic diseases.

The study aligns the novel with key principles of patient-centred care. It offers a new perspective on how to use children's fiction to promote patient-centred care. The practical and ethical dimensions of this model are discussed in the study. Yohalem, through her characters, explicates the relevance of recognising the active participation of children in their healthcare management, which generally follows a paternalistic framework. It also calls for giving respect to individuality and independence in paediatric treatment. The prevention of misinformation through proper communication and integration of emotional support are ideas that are analysed in the study. Therefore, the research strengthens the requirement of transforming paediatric healthcare into a collaborative partnership model.

Highlighting the importance of health literacy in young people through the medium of children's literature is another notable inference of the study. Children's literature can be an active medium in encouraging public health education, reducing stigma in relation to disease and correcting misconceptions surrounding chronic illness. Additionally, the study implies that such narratives can extend psychological and existential support to young patients. By discussing the daily lives of long-term diseased individuals, these stories support identity construction and contribute to emotional resilience among young patients. Overall, this research affirms that juvenile fiction has transformative potential within health humanities.

Conclusion

This study indicates that *The Truth According to Blue* by Eve Yohalem is not only a middle-grade adventure fiction but also a paediatric narrative with great depth. The portrayal of Blue Brion's daily life as a Type 1 diabetic girl exposes the real social, emotional, financial and existential dimensions of the disease. While situating the novel within the scope of health humanities scholarship and its interdisciplinary framework, the study highlights the expanding scope of children's literature. Juvenile fiction also holds the ability to function beyond the role of entertainment. It can be an active participant in the realm of medical discourse and ethical reflection. By positioning the novel with the eight core principles of patient-centred care the study states how children's fiction can serve as a meaningful and

ethical resource. The narrative magnifies the value of paediatric autonomy in the course of treatment and showcases how to reclaim dignity, individuality and agency in a paternalistic model of paediatric healthcare. The article also sheds light upon the complex realities of similar diseases, contributes to health literacy and provides solidarity to young patients living with chronic illnesses. Ultimately, the study argues for acknowledgement of paediatric illness narratives as valid and valuable elements of health humanities discourse.

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