International Journal of Literature Studies

ISSN: 2754-2610 DOI: 10.32996/ijts

Journal Homepage: www.al-kindipublisher.com/index.php/ijls



| RESEARCH ARTICLE

"What if I lose my ability to language?" A psycho-social interrogation of the Language disorder narratives in bioscope and Literature; a Phenomenological analysis

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ABSTRACT

The prevalence of inadequacy in the levels of comprehension, when it comes to an individual undergoing health imbalance is still a repressed concern. With comparatively minimal exposure on Language disorders3 in the Indian context, the construction and provision of an appropriate milieu that suffices the psycho-social4 needs of the individuals is a pressing priority. "Inclusivity" as a terminology has been gaining momentum in a multitude of spaces and yet the convalescing journeys of the individuals whose disruption of their ability to language1, prevails as an under-represented and undocumented arena of research and representation. This study is an attempt towards mainstreaming the media and literary documentation of pathographic narratives (especially language and communication disorders, i.e. Aphasia2) that aim at transforming the obscure knowledge of language disorders among the population into an agreeable scholarship creating a platform for a better psycho-social environment. This study is a representation of the muted outcry of those experiencing language disorders and in addition an attempt in channelizing the need for a global digital space that merges literature and media representations of the same. This study highlights the convergence of literature (The Man Who Lost his Language), media (My Beautiful Broken Brain) and sociology in thriving towards a socio-centered environment in India.

KEYWORDS

Inclusivity, Pathography, Health narratives, Aphasia, Dysphasia, Phenomenology, Language disorders, Language disruption, Stroke

ARTICLE INFORMATION

ACCEPTED: 12 March 2025 **PUBLISHED:** 05 April 2025 **DOI:** 10.32996/ijts.2025.5.1.4

INTRODUCTION

"Exclusion is always dangerous. Inclusion is the only safety if we are to have a peaceful world".

(Pearl S. Buck)

Inclusion is a phenomenon that is gaining prominence across multiple disciplines and Inclusion in the current discussion is being contextualised in the field of health and wellness. One of the hallmarks of social wellness is being inclusive (Laurie Buchanan), this inclusivity is desirably achieved only when the obscurity (in terms of knowledge) is transformed into an agreeable scholarship. The current discussion centers on Language disorders (Aphasia², Dysphasia⁵) wherein the language system is lost or disrupted as a post-stroke complication. The works chosen for discussion *The Man Who Lost His Language* by Sheila Hale⁶ (representing the Literary narratives) and *My Beautiful Broken Brain*⁷ (representing the media portrayal) encapsulate the instances, catastrophic incidents and the aftermath complications that strokes bring into lives. The narratives showcase the

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loss of the language components and expound on the marked variance in the life before and after stroke and how it has a tumultuous impact over their physiology and psychology. Language disorders as a post-stroke complication⁸ result not only in physiological shortcomings but also present the affected individual with changed realities in their lives, in terms of the psychological⁹ and sociological environments. Awareness survey on Language disorders like aphasia¹⁰ among the Indian population stands testimonial to the necessity for discussion of the same which could aid in better comprehension of Language disorders, the impacts and how the efforts towards inclusion could propagate for a balanced psycho-social environment among the population. The preponderance of this need results from the uncertainty of the population on Language disorders. In attempts of mainstreaming the pathographic¹¹ narratives the study engages in enhancing the limited knowledge revolving around language disorders which hinders in fostering a heightened inclusivity for individuals experiencing speech impediments, in turn forging a balanced psycho-social environment.

Thesis statement

The unaddressed gap in attaining absolute scholarship of Language disorders like Aphasia and Dysphasia contribute in an inadvertent habitation of the Aphasics and the Dysphasic on social and psychological levels. The inclusivity of those experiencing language disorders The indispensability of transforming the uncertainty of language disorders and their reality among masses which could foster an inclusive environment in the event of enhanced awareness and comprehension, stands as the primary focus of the study.

Purpose of the study

The prevalence of Aphasia¹² among Indian population and the need for enhanced representation in terms of their psychological and sociological conditions through Literature and media and how the digital technologies can serve catalytic in thriving towards an inclusive environment for Aphasia and other Language disorders is the purpose of the study.

INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

Phenomenology (objective conception/interpretation of subjective experiences or realities) and Hermeneutics (interpretative methodology) serve as the origin of the theoretical framework of Interpretative Phenomenology¹³. Interpretative Phenomenology differs from phenomenological psychologies in the aspects of understanding the psychological stature and experiencing the subjective realities as objective experiences. In Literature¹⁴, Interpretative phenomenological analysis is the attempts of centralising the lived experiences of individuals of the study into an augmented reception and comprehension in order to inform and enhance the knowledge regarding desired subjects. Jonathan Smith, Michael Larkin, Paul Flowers propounded the theory of Interpretative Phenomenological Analysis. IPA is an attempt towards understanding complex realities and emotional experiences through a detailed analysis rather than a surface level interpretation of objective facts¹⁵ (Jonathan Smith, 1990). This theoretical framework is better suited for the study in perceiving the complex realities of Aphasics and Dysphasia¹⁶ which can only be comprehended on a superficial level, as is the prevalence of every health complication. The impracticality for an unmediated experience of health complications by the masses creates a grey area for a complete comprehension and empathy towards those encountering health imbalance. Under such pressing situations, Interpretative Phenomenological Analysis(IPA) aid in achieving an enhanced manifestation and perception. IPA attempts to document the pressing priorities demanding attention and awareness¹⁷ rather than the linear instances that drive home generic facts.

INTERPRETATIVE PHENOMENOLOGICAL READING AND RECEPTION OF THE LITERATURE AND FILM ON APHASIA AND DYSPHASIA

Representation of Aphasia and Dysphasia in the literary and media forums are an undeniable essay in showcasing the worlds of individuals undergoing Language disruptions due to underlying conditions. It is this mapping of the gap in the awareness, understanding and inclusiveness of the above mentioned individuals in societal settings that structures the indispensability of the study. The following excerpts account for the lives of Aphasics and Dysphasics presented from the view-point of the caregiver and the individual undergoing Dysphasia which are perceived to foster improved scholarship. The excerpts are followed by an interpretative phenomenological description of the subjective realities perceived as objective reception.

The Man Who Lost His Language: A Case of Aphasia

This work is a memoir centering on the life before and after the advent of geriatric stroke in the life of John Hale, historian and author, documented by his spouse, Sheila Hale. This work of pathography in Literature is an indispensable contribution towards an encapsulation of Aphasia and the life of an Aphasic during and after the incidence of stroke. John Hale is faced with geriatric stroke and extreme symptoms of Aphasia. The incidences of occurrence, experience and impact of Aphasia in the words of the narrator and care-giver, Sheila Hale are excerpted. The narration documents and draws upon references that vocalise the incidence

of stroke and Aphasia and establish relevance in aims of delivering the facts with utmost clarity and detailed depiction of the actual incident.

Nothing at all makes sense. Nothing except perhaps this overwhelming disorientation will be remembered by the victim...the victim's mind, her sense of time and place, her sense of self, all are being shattered if not annihilated. (Arthur Kopit, preface to Wings, the stroke survivor's experience of the incidence)

With John Hale losing his ability to speech and left with just the words, *da woahs*, Sheila Hale inter- texualises²⁰ the turmoil that can only be conceptualised. His experiences are perceived and predicted since his ability to express is deprived. With communication laying the platform for expression¹ among the humankind, the loss of language deprives the individual's ability to articulate, vocalise and express their experiences leaving no room for channelling their psychological distresses and sociological impediments in entering the society.

If I had known what that look meant, it is theoretically possible that I might have saved John – at least in the unlikely event that an Accident and emergency department had seen him immediately, recognized the symptoms and taken action in time. (Hale, The Man Who Lost His Language, 2013)

The experiences of Sheila Hale during her husband's stroke and Aphasia aims at educating the reader, regarding the subject and the need for psychological equipping that is indispensable in acting at the right time and accessing the healthcare facilities in such stipulated time frames which in most cases determine the chances of lessening the intensity of progressive damage.

He was thinking very hard, trying to think a way out of his dilemma, and he needed no words to tell me that the only solution he could find was suicide...He pushed me away. He opened his mouth and pulled at tongue and lips. He grabbed a pencil and scribbled violently in the air then threw it on the floor. He did a wordless imitation of himself trying to enunciate words. He mimed himself as an idiot, head lolling, index finger in his mouth, eyes rolling. He began to talk in his wordless voice. I listened and realised that I understood what he was saying. With a phonetic range more restricted than a baby's he spoke to me by modulating his voice; its pitch, rhythms, timbre, timing, intensities as eloquent as ever. (Hale, The Man Who Lost His Language, 2013)

The hard-hitting realisation of the changed reality and the inability to make amends or attempts in gaining what has been lost is a never-ending labyrinth that keeps you in the momentum of falling endlessly. This excerpt of Sheila Hales's depiction of the behaviourism of John, on his realisation of the impacts of his stroke document the helplessness that John experiences and the turmoil of emotions that range from distress to frustration to rage is comprehended through a close reading of the above excerpt.

I reminded him that he had always believed suicide to be the most disgusting and unjustifiable of acts, as immoral as murder. (Hale, The Man Who Lost His Language,2013)

This excerpt is the display of psychological extremity that John faces due to his inability to speech. Having had the proficiency in language skills for over seventy years, the changed circumstances collapse his control over the psychological coping of his current reality.

My beautiful broken brain

My beautiful broken brain¹⁸ is a documentary film starring Lotje Sodderland, a 34-year-old who experiences a cerebral haemorrhage resulting in Aphasia, in the initial stages after regaining conscious and Dysphasia in the later stages. This film is a documentation of the actual experiences of the protagonist herself, after the incidence of stroke. The film presents to the viewers the incidence of stroke, the aftermath and the consequential changes in the life of Lotje. This film is inclusive of the video graphic footages that Lotje recorded of herself during her treatment for the haemorrhagic stroke in the year 2011. The episodes showcasing Lotje's experiences during and after the stroke are amalgamated with the producer's attempts in visualising the differences in the world of a dysphasic stroke survivor. The incidences of stroke and episodic lapsing of language during the course of recovery by Lotje on the 7th of November, 2011 have been showcased with no variations to facilitate better comprehension among the audience.

The film unravels with the replication of the moments in the life of Lotje Sodderland during the incidence of her haemorrhagic stroke¹⁹ The disorientation experienced by the protagonist and the helplessness due to the moment's despair leaves Lotje undergoing a psychological turmoil and psychological turbulence on account of the haemorrhagic stroke. By the time that she

reaches out for help, she had lost her ability to language which had the transitioned into Aphasia² The admission for treatment and the episodes that shortly follow are comprehended through the video graphs that Lotje had recorded post her recovery from the unconscious state. The narratives of Lotje's brother, Jan, her mother, Ant, Lotje's colleague, Barney and Lucy, friends of Lotje, Henet, Lotje's mother are incorporated in the course of the film which add precision to the occurrences and provide a holistic view-point of the incidence in itself. The narratives of those that found Lotje in the most vulnerable state during the incidence of stroke and the loss of her ability to language, provide a detailed description of how the life of Lotje had undergone a change which is not subsequent but drastic and how her ability to strive for gaining back her control over her life through the improvement in her language system served as the key to her successful story of survival.

The documentary film is partly narration and majorly video graphic which enables the audience in engaging with the adversities of Lotje on a psychological level drawing parallels between the multiple narratives of the protagonist and her immediate circle and the recordings of her experiences of stroke during the year 2011. Lotje's encounters of language disruption is presented through her medical appointments with the speech therapists. The unacceptable realisation of the loss of language in spoken and written forms falters hopes and inhibit psychological breakdown. Episodes of Aphasia² soon transformed into Dysphasia¹⁶ where the ability to vocalise her thoughts were challenging yet attainable but it was the loss of written language that put Lotje to the starting line in the life's race. Lotje's stroke compromised not only her ability to Language but also resulted in changed or heightened sensory perceptions and colours. This change also affected her psychological balance amidst striving to relearn language. With heightened sensory experiences the routine of Lotje is a distorted reality wherein the dispense of colours to her eyes is drastically intensified and the sounds received in extremity. With this imbalance in the vision and auditory senses, the management of daily tasks proved challenging. The documentary film summarizes every episode that individuals with Aphasia and dysphasia encounter and it is at this juncture that the primary goal of bringing into broad arena the prevalence of stroke and its impacts on the survivors is met. The film is a precise documentation of a year in the life of Lotje Sodderland when she experienced stroke. The day of the incidence to the recovery, Lotje aimed to present and bring to the audience's notice the prevalence of stroke and the post-stroke complications that are under-discussed. It has been her initiative in approaching David Lynch, the directors and producers in bringing her experience into an augmented production of filmography.

DISCUSSION AND CONCLUSION

ROLE OF LITERATURE AND MEDIA IN A HUMAN-CENTERED APPROACH TOWARDS ACHIEVING INCLUSIVITY FOR APHASICS AND DYSPHASICS

The memoir by Sheila Hale and the film of Lotje Sodderland by David Lynch stand testimonial to the human-centered approach that the literary and entertainment industry adopt in fostering the indispensable awareness²¹ on the needful subjects that result in optimal knowledge and wisdom to stimulate inclusivity. These works of literature and cinema are attempts of the individuals who had been acquainted with changed realities whose primary aim has been to increase the awareness on the subject of stroke and language disorders and facilitate an improved environment that lighten the burdening of their changed lives. With the lack of optimal awareness prevails a tumultuous hindrance to achieving a society that is accommodative of Aphasic and Dysphasic friendly environment. In the case of individuals undergoing language disruptions it is the very ability to their language that is being deprived. The aptitude for expression of thoughts, emotions and correspondence through language becomes impractical. It is at this juncture that literary and media portrayals of Language Disorders gain prominence and vitality. The last two decades have undeniably presented the audience with discussions that are sociological and psychological subject matters that benefit the convalescents' livelihood. With the above stated literary and cinematic portrayals of pathographic themes, an environment better suited for the stroke survivors whose psychological needs empathised and sociological needs met, can eventually be achieved and attained. With improved proficiency over sociological issues comes the road to inclusion and fellow affinity.

LITERATURE AND BIOSCOPE IN FOSTERING IMPROVED SCHOLARSHIP ON THE LIFE-ALTERING LANGUAGE COMPLICATIONS

The impracticality revolving around the complete understanding of a health complication is an agreeable notion with regard to the lack of experientialism among every individual in a society. Literature and bioscope venture into the possibility of challenging this hindrance by producing works that vocalise the personal narratives/first person narration of the individuals concerned. Literature maps this gap by vernacularizing pathographic narratives which are a divergent from the medical paradigm in facilitating successful reception and comprehension among readers. Bioscope in the current discussion, presents itself as a continuum of literature in achieving replica of the distorted reality of Aphasics and dysphasics which can be made possible through no other means. The replication of the changed reception in auditory and visual senses among the dysphasics is an arena which has undeniably been successfully rendered by bioscopic productions. Literature on the other hand provides voice to the repressed psychological and sociological concerns and depict the lives of Aphasics and the Dysphasics in a multitude of perspectives that aid in conveying their physiological, psychological and sociological state of affairs.

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The above articles detail on the thematic representation of identity and self, acceptance and advancement into the changed realities and the analysis of the episodes of linguistic disruption in the documentary film, My Beautiful Broken Brain.

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The above articles centre on a detailed summary of Aphasia and the medical paradigmatic depiction of the condition. The review of the literatures drives home the understanding of the marked variation that the current study exhibits from the existing canon of literature which is the consolidated representation of physiological, psychological and sociological concerns that surround the pathographic narratives of Sheila Hale and Lotje Sodderland.

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