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Review Article

Narratives of Resilience: Unveiling the Human Side of Cancer Amidst the Covid-19 Era

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A B S T R A C T

Health and medicine, as an instrument of interventional and therapeutic interaction, encompasses both public and popular culture. The labels 'cancer' and 'cancer patient' evoke overwhelming stress. During the course of the disease, cancer patients are required to make multiple visits to hospitals for clinical examinations, laboratory and imaging tests, and different types of medical procedures and surgical intervention as part of the diagnosis, staging, and monitoring of the treatment regime. The Covid pandemic has further exacerbated the challenges faced by the immunocompromised cancer survivors, sometimes affecting their access to treatment and care. The paper examines in detail the first-person accounts furnished by cancer survivors as well as the physicians who treated them, with the intention of gauging the extent to which the pandemic impinged on the prospects of cancer patients and cancer survivors getting diagnosed, treated and continually cared for. The cancer testimonials studied herein invariably point to the fact that the very act of reflecting on the journey of their struggle, especially during the adverse times of a pandemic, and sharing their experiences with others makes them feel empowered, both against the disease and the systemic discriminations inherent in the medical establishment. The article emphasises the need for compassionate communication and open conversation to address the challenges posed by Covid-19 in the cancer community.

Keywords: Covid-19, Cancer, Illness Narrative, Medical Humanities

Introduction

Medical Humanities, which surfaced in the latter part of the twentieth century, is an evolving scholastic branch involving an interdisciplinary field of enquiry that draws on history, ethnography, anthropology, sociology, cultural theory, psychology, philosophy, religion, bioethics, and even literature, essentially tracing their interrelationship, and investigating the pathological consequences of crises in this relationship. It began as an academic initiative aimed at cultivating the humanistic characteristics or aspects of medical practice within the medical institutions of the United States of America in 1972. Medical humanities may have been conceived as a holistic methodology that took into account the mind and body of the diseased, the pathological cause and physiological symptoms of the ailment, the sociological and individual implications of clinical diagnosis and treatment, and the psychological and pharmacological aspects of healing. As cited by Brian Hurwitz in his journal article titled "Medical Humanities:

Lineage, Excursionary Sketch and Rationale", the term was coined by George Sarton and Frances Siegel in 1948, in a journal named ISIS in relation to the history of science, and sought to redeem those empathetic skills which were fast eroding from the medical fraternity as a consequence of the rigorous training regimen and emphasis on practical aspects in modern medical education.[1]

The Covid-19 pandemic has brought a tumultuous shift in the global health dynamics, impacting individuals and communities across the globe. In March 2020, the World Health Organisation declared Covid-19, which was first reported in the Chinese city of Wuhan, a global pandemic. Conspiracy theories and international blame games surrounding the illness have been as intolerable and odious as the pandemic itself. The pandemic, however, had the effect of rekindling the focus on medical humanities as a viable and more holistic trajectory of the medical science that has been dealing with diseases exclusively in terms of chemotherapy and surgical procedures, to the total neglect of all alternate and parallel paths of health and healing.

A pandemic caused by a particular strain of virus which is on a consistent path of self-mutational dynamics affects not only the well-being of people who are otherwise healthy but also the lives of the critically ill who are already under the care of the medical system. However, during Covid-19 the resources of the medical science-based healthcare delivery system in many countries were unevenly spread out to focus on Covid patients, without any preferential approach to patients with a history of other physiological ailments. Some of the prominent victims of circumstance in this context included expectant mothers, patients who were on dialysis after renal failure, cancer patients and cancer survivors. People with reduced immunity, such as cancer patients, are more prone to contracting infections. There are many varieties of cancer based on the original tissue from which they arise. Cancer in organs directly related to the immune system like leukaemia is likely to cause worse outcomes when compared to solid tumours. Covid-19 is reported to have caused serious illness and mortality in cancer patients, further exacerbating the challenges they had to face. The rigours of social distancing put in place during the pandemic seem to have caused much difficulty for them in getting access to proper treatment and quality healthcare.

The intersection of cancer and the Covid-19 pandemic presents a unique opportunity to delve into the experiences of individuals facing the dual challenges of the illness and a concomitant public health crisis. The discipline of "medical humanities" redefines the understanding of health and illness to sensitise multiple stakeholders such as carers,physicians, patients, paramedical staff, and even the civic administration to a more benign acknowledgement of the subjective experience of illness, in absolute contrast to the objective rigours of "medical science". This research will focus on narratives of resilience among cancer patients, with a particular emphasis on those navigating their illness during the Covid-19 pandemic. The study draws upon qualitative methods of textual analysis to scrutinise personal accounts shared by cancer patients, which further offers insights into their psychological, emotional, and social dimensions during these tumultuous times. Understanding these narratives is essential for supportive interventions, shaping healthcare policies, and fostering greater empathy and understanding within society.

The paper in particular examines the first-person accounts of the experience of three cancer survivors: Dr. Bill Gardner, a psychologist who currently holds a teaching position at the School of Epidemiology and Public Health at the University of Ottawa, Sarah Sanders, a thirty-five-year-old, triple-negative breast cancer survivor from New York City, and Loriana Hernandez, an Emmy award-winning journalist from Texas who is the author of Becoming the Story: The Power of PREhab (2021).[2] Hernandez is a leukaemia survivor and a breast cancer patient. As the world continues to navigate the complexities of the unprecedented crisis, the emergence of narratives of resilience offers a lens to explore the human side of cancer amidst the Covid-19 era.

Cancer Narratives as an Eye-opener During Covid pandemic

Medical or health humanities facilitate compassionately nuanced and meaningfully accommodative conversations as a more effective and congenial mode of engaging with diseases. The disciplines of art and aesthetics and the social sciences together come to play a decisive role in comforting, motivating, and possibly empowering individuals to openly discuss their experiences, apprehensions, and sentiments in such a way as to promote resilience and foster connections within communities. The relevance of the cancer narratives produced during the pandemic remains in the fact that they provide significant information and advisory insights on the individual and social aspects of patient care in terms of illness management and psychological sustenance. Further, these accounts serve as instructive examples shedding light on the challenges posed by a pandemic like Covid-19 in the cancer community. These narratives enumerate a host of adversities and difficulties faced by cancer patients and survivors during the pandemic, which include curtailed access to clinical care, deficient psychological support, scarcity of channels of communication within the community and overall degradation in the quality and wellness of life. A common denominator traced across all these accounts is the autonomous mobilisation of the feelings of optimism and empowerment that the very activity of writing or speaking about their experiences seemed to bestow on their creators.

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As the current generation of humanity grapples with a disease of unprecedented nature and magnitude, medical literature based on clinical findings and surmises essentially undergoes constant evolution, as it has to accommodate corrections and additions almost on a daily basis. This is because human beings – high-end professionals and the layman alike – are dealing with a disease that has the capacity to pose fresh challenges and rigorous obstacles to those who try to contain it on a daily basis. Even then, each of these narratives of illness, howsoever fleeting the observations are, are self-validating as they contribute to a collective corpus of historiography that deals with the human experience of fighting against a once-in-a- lifetime health calamity. It might be attributed to the fact that there is some kind of meaning- making at play when people afflicted with a potentially fatal disease like cancer choose tocommunicate or share their experiences with others, simultaneously articulating the inner psychic dislocation the Covid-19 pandemic had caused in them. Cancer patients, being immunocompromised, are at a higher risk of mortality during a pandemic, and they feel doubly jeopardised under the socio-economic rigours during a pandemic. Narrating illness is surely a means through which they try to alleviate their sufferings, and as they voice their issues for the readers or listeners to bear witness to their experience, it becomes a collective resistance to a traumatic experience. The primary objective of this research is to explore the narratives of cancer patients amidst the Covid-19 times. Specifically, the study highlights the significance of these narratives in shaping perceptions, attitudes, and support systems for the cancer patients in the current health landscape. Further, it analyses the personal accounts of cancer patients, their challenges, coping strategies, the role of resilience in navigating the intersection of cancer and pandemic. These stories of flesh and blood have the power to heal, to correct and to instruct, and it is hoped that they will outlast the pandemic.

Theoretical insights from Medical Humanities

As recorded by Ann Jurecic, Professor of English at Rutgers University in New Brunswick, Canada, and Associate Editor of the John Hopkins University journal Literature and Medicine, in her work Illness as Narrative (2012)[3], "illness narrative as a literary genre began by the late twentieth century". She sees the growth of illness memoirs not as a collapse of literary standards but as a logical consequence of the change of culture, medicine, and society.[2] The emergence of illness narratives as a specialised branch of literary composition in the last fifty years has been largely the result of a realisation that the cyclical engagement between pathogens, patients, physicians and social institutions operates on a much deeper and microcosmic level than envisaged by the medical science establishment which works exclusively on the therapeutic model. The notion that the human mind is at once an enigmatic source as well as a sensitive witness to physiological and anatomical illnesses of the body has been instrumental in bringing to prominence the illness perception of patients, which constitutes their beliefs and thoughts and the treatment process as something worthy of serious consideration. In the article titled "Illness Narratives: Reliability, Authenticity and Empathic Witness" (2011), Professor Johanna Shapiro, Department of Family Medicine, University of California Irvine Medical Centre, defines the essence of illness narratives as: "all narratives are the results of authorial decisions, made for a variety of aesthetic and personal motives" (68).[4] Hence, it can be inferred that illness narratives in their most pertinent form serve to demonstrate the role of the patient's psyche in the healing function of the therapeutic process. Thus, the therapeutic process also presupposes an orientational change in the relationship and interaction between the patient and the physician and brings in a lot of alternate agencies and instruments extraneous to the medical establishment into the therapy.

Dr. Rita Charon, an American physician and the Founder-Director of the Graduate Program in Narrative Medicine at Columbia University, articulates in her seminal work, Narrative Medicine: Honouring the Stories of Illness (2006), the conceptual framework of narrative medicine. This discipline encompasses a diagnostic and holistic approach that integrates patients' narratives within the realm of healthcare delivery and investigation and facilitates the process of healing. Central to its ethos is the recognition and exploration of the relational and psychological facets concomitant with physical illness. Thus, narrative medicine is fundamentally rooted in the validation of individual patient experiences, emphasising the significance of each patient's personal narrative or 'story' (Charon 2), fostering empathy through genuine engagement and control.[5] This foundational concept finds empirical validation within the context of cancer testimonials selected for the study.

The notion of 'human self-concept' as espoused by the Professors of Psychology, Simine Vazire and Timothy D. Wilson, in their work, Handbook of Self-Knowledge, encompasses the holistic image individuals hold about themselves: it embraces various dimensions of perception, including physical, emotional, social and environmental factors that shape their identity ("What is self-concept?").[6] This psychological construct undergoes a gradual developmental process and is seen to constantly evolve through discrete elements such as self- esteem, ideal self, and self- image, as expounded upon in the journal JournalPsyche, by the humanist psychologist Carl Roger in the article titled "Revisiting Carl Roger's Theory of Personality".[7] The significance of a well- developed self- concept is such that it facilitates for individuals an understanding

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of their intrinsic value and the subsequent benefits it confers upon their lives. Additionally, the intricate ways in which 'self-concept' exerts influence on an individual's perceptions and notions could be said to be engendering a progressively evolving set of strategies for individuals to navigate and respond to problems and conditions that crop up from time to time. Life narratives, especially illness narratives, attain significance as comprehensive records of a constantly evolving trajectory of perceptions and responses with respect to the illness and the therapy, as shaped by the patient's self-concept. Analysing illness narratives in the light of the aforementioned concepts, enables the physicians to understand the experiences of the patients better, and also to recalibrate their own roles in the therapeutic process. These narratives highlight the ways in which the notion of illness is constituted and negotiated within individuals and communities experiencing suffering. It simultaneously empowers the patients to voice their experiences, perceptions, emotions, anxieties, and even the details of their contact with alternate sources of comfort and healing that remain exterior to the patient-physician-medicine triad.

Cancer's tryst with Covid

Cancer narratives, produced during the pandemic, Covid-19, attain special significance against the backdrop of the twin factors of patient empowerment and exploration of alternate therapeutic points. Bill Gardner, in his cancer journal The Incidental Economist, writes about his experience of dealing with oropharyngeal squamous cell carcinoma, which he developed during the pandemic.[8] Loriana Hernandez, a Leukaemia survivor and breast cancer patient, narrates in the ABC News YouTube video titled "Battling cancer amid COVID-19 outbreak", her concerns about being at high risk for coronavirus and how she kept herself healthy.[9] The YouTube video titled "This Cancer Patient's Resilience During Covid-19 is so powerful" uploaded by Katie Couric, deals with the breast cancer testimonial of Sarah Sanders.[10]

The official website of the National Cancer Institute, United States of America, defines cancer as a condition "in which some of the body's cells grow uncontrollably and spread to other parts of the body" ("What is Cancer?").[11] These cells continually divide to give rise to a mass of cells called 'tumours. Early detection is crucial to the success of the treatment of the disease, as cancer cells have a tendency to replicate themselves rapidly and also because the carcinoma can spread to other organs too. Cancer detection is done on the basis of multiple diagnostic procedures including radio-diagnosis, biopsy and histopathological studies of the affected tissue and the blood. Bone marrow tests are also undertaken for the detection of abnormal an increase in cell count in the case of leukaemia. Most cancers are addressed through a combination of surgery, radiotherapy and chemotherapy. All through the course of the treatment, which involves multiple components, what has proved to be most vital and essential in sustaining the physical endurance and mental fortitude of the patient is a well-defined mechanism of palliative care.

Bill Gardner, a psychologist and a researcher in the field of community health service, narrates his personal experience of throat cancer (oropharyngeal squamous cell carcinoma) which he was diagnosed with during the Covid pandemic. For him, cancer was a personally transformative experience. It becomes clear that his progressive narrative engagement with the disease at various stages of the therapy must have helped Gardner attain what Carl Rogers calls a 'well-developed self-concept', which in turn instilled in him a positive approach towards the daily challenges posed by the life- threatening disease, especially against the backdrop of Covid-19. There was a perfect blend of self- image, self-esteem and ideal self.

Gardner recognised symptoms of cancer in December 2020, when Covid-19 was at its peak. He writes: "Covid has put exceptional stress on provincial hospitals…so not a time when you can expect quick response". He also acknowledges that, "By US standards, the Canadian health care system is conservative in its use of diagnostic procedures; that is, they think that less is often more. So, there are, by US standards, delays in getting images or scans" (Gardner 1), and sometimes he had to be diagnosed "in the hallway" (Gardner 10). Even though a PET scan of the carcinoma was done in early December itself he could get an appointment with the oncologist only in January 2021. "Hospital beds are of hundred percent occupied, no beds, acute or chronic care beds" and cases that required hospitalisation increased at an alarming rate, and the available beds were nothing (Gardner 11). Gardner overcomes the trauma and the confusion caused by the disease, and more than the disease, by the delay in getting the disease treated, through a semi-humorous narrative negotiation with the pathological condition of his body, whereof he remarks: "The upshot is that I am now a cancer patient during the COVID-19 pandemic" (Gardner 1). As the Covid patients were the urgent care category, there was obviously an inevitable scarcity of resource allocation for other categories of patients in the health care system.

Gardner reminisces that his interactions with the radiologist had helped him gain new insights on the trajectories of cancer treatment. "On July 9th, I spent the day at the Cancer Centre meeting with my radiation oncologist, and I learnt a lot" (Gardner 2). The physician had explained to him the cause of the cancer and had advised him to get a Computerised Tomography (CT scan) and to undergo a tracheotomy. Gardner acknowledges that the doctor

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was liberal enough to accord the patient the freedom to engage in medical discussions concerning various treatment options, such as choosing between surgery, radiation, or chemotherapy, and that he was also accommodative of the absolute right of the patient to give or not to give his consent for the treatment. Gardner's experience self-avowedly demonstrates the presence of what medical humanities identifies as 'patient autonomy' in clinical practice, something which had been denied to the diseased during much of the nineteenth century. A few pages later he writes that the thought, "But I am more than just me," started to nag him, as he had his wife and five children waiting for him. As he himself observes in his narrative, the preliminary stage of charting the course and schedule of the treatment marked the beginning of a long sojourn in which the doctors had taken the patient into absolute confidence. He says in his narrative that he got aid and advice from several physicians at the Ottawa hospital, for which he was grateful, as they always cleared his queries in a respectful manner and went a long way in helping him to manage the physical and mental trauma caused by the cancer and enabling him to finally overcome the pathological condition that had affected him. The experiences of the patient as they get charted out in an illness narrative gain a great deal of relevance by contributing to a comprehensive body of medical knowledge in which the psychodynamics of the patient are equally relevant as those of the diagnostic procedures and pharmacological intervention in the process of healing. It is against this backdrop of a holistic treatment protocol which values the patient's perspective of the illness that the new concept of 'narrative medicine' has emerged.

As it turns out from the narrative, cancer, or for that matter any other serious ailment, either of the body or of the mind, is a condition that is most effectively addressed with the help of multiple agencies through multiple angles. The doctors who did not have any delicacy in revealing the details of the disease and were candid enough in making him realise the seriousness of the condition later turned most empathetic and encouraging in the battle against the carcinoma. The attention and the care he received from his family, the support of his friends, and the reassurance provided by cancer survivors, he acknowledges, were crucial in sustaining him through the difficulty and were of invaluable help in enabling him to endure the traumatic phase of the therapy. Further, his own inner resources, including religious faith, patience, love, and optimism, he says, had a profound role to play in seeing him through one of the most difficult periods in life. In the final reckoning he gives credit to all these internal and external factors as significant elements of the therapeutic process: "I am grateful to several physicians and cancer survivors, compassionate strangers who read my post and wrote to me. Thanks to you all (Gardner 4). Many messages of support made him feel good, as Garnder says that being a cancer patient is a struggle. The compassionate attention that people offer is indeed an antidote for the immunocompromised survivors. To Gardner, this gave the feeling that he was not alone and someone was there to comfort him throughout the meandering course of his cancer journey. Gardner remarks that "shared decision making worked superbly for me", but also admits that he was accorded this liberty in recognition of his professional identity as a doctor (Gardner 4). This would mean by extension that it would work in the case of ordinary cancer patients too, if they were given a limited extent of participatory feeling in the fight against cancer. Life narratives of cancer survivors thus acquire an academic significance in throwing up fresh insights meant to strengthen the treatment protocol.

As a cancer narrative, Gardner's writing acquires greater significance as it talks about the experiences of fighting cancer during a global pandemic that tied people down to their homes and placed a huge strain on an already stretched healthcare edifice. As the pandemic drew the healthcare professionals including physicians, nurses, pathologists and other support staff disproportionately to the Covid warfront, there was large-scale cancellation of elective surgeries. "My cancer care halted because the pandemic is breaking Ontario's health care system" (Gardner 14). Cancer made the harsh truth of mortality deeply personal for him. Gardner emphasises that: "And here is my final point: I am not fighting cancer because cancer is not the true enemy. The enemies are death and suffering; cancer is just one of the myriad causes of affliction" (Gardner 22). As the regular channels of medical therapy got partially blocked due to the mobilization of all medical resources in the fight against Covid, people who were afflicted with other life-threatening diseases, including cancer, were forced to resort to alternate sources of healing which lay dormant under the colossal influence of the 'biomedical industry'. The nexus between profit-mongering pharmaceutical giants, unethical medical practitioners, and corrupt bureaucracy had almost reduced medical science to a unidimensional entity involving just the physician and the medicine. In this context, Gardner's narrative proves to be a game changer by way of its capacity to anticipate a transition from medical science to medical humanities as a more holistic approach to healthcare. Thus, the illness addressed against the backdrop of the pandemic could be said to have given him an opportunity to view life from different angles, which he might otherwise not even think of.

The YouTube video titled "Battling Cancer amid COVID-19" uploaded by ABC News shows Loriana Hernandez, a leukaemia survivor and breast cancer patient from Texas, narrating her concerns regarding the difficulties faced by critically ill cancer patients in accessing hospital resources

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during the pandemic. She says that the Johns Hopkins Hospital, despite being a global leader in fighting Covid-19, did not find it safe to permit cancer patients on hospital premises. This in turn obstructed the routine schedules of check-ups and paramedical tests which were quintessential for her recovery from the illness. She was emotionally, physically and psychologically down, not because of the cancer, but due to the lack of access to a support system that was a crucial part of the fight against cancer. Besides, adding to the trauma, there was always the fear of contracting the novel Coronavirus from her minimal contacts with the outside world. However, she took a confident stand and was determined not to lose hope. She says that the alternate treatment protocol that was put in place during Covid-19 enabled her to experience a new kind of life within the four walls of her home. When most people were frustrated by the lockdown, she found it an absolutely perfect arrangement whereby her cancer would be addressed, and at the same time, she and her loved ones would be shielded from the deadly virus. These words of Hernandez constitute a kind of testimonial in support of the emerging concept of medical humanities, as they are actually about the possibility of invoking factors extraneous to the doctor and the drug in the battle against cancer.

In the YouTube video titled "Covid-19 and Cancer: The Challenges for Doctors, Patients, Nurses" uploaded on the channel 'Doctorpedia', Dr. Adam Boruchov, a reputed haematologist working at Trinity: Health of New England Medical Group in the United States, is seen raising his concerns about the transmission of the novel coronavirus from the doctors and other healthcare workers to the patients, and in turn, from the patients to their family. He mentions the safeguards put in place by the hospital administration, such as ensuring rigorous social distancing, limiting visitors, and making pre-visit telephonic appointments mandatory. "We had a very low threshold to treat patients as PUI, patients under investigation", he reports ("Covid-19 and Cancer" 3:48- 12:32).[12] The pandemic necessitated certain ad hoc changes to be made in the standard treatment protocols generally followed by medical establishments, and the most compulsive among them was to alter the dosing of medicines and the frequency of clinical examinations in order to reduce the risk of the patients getting exposed to the virus within the hospital ("Covid-19 and Cancer" 4:17- 12:32). Dr. Boruchov is seen admitting that it was incredibly distressing to see the immunocompromised cancer patients trying desperately to sustain themselves on the pre scheduled course of treatment during the pandemic. The experience of many of the cancer patients was heart-wrenching, and some of them eventually passed away in complete isolation. Boruchov's confession points to the ultimate reality that medical science, in its exclusive focus on the diagnostic, the paramedical, the pharmaceutical, and the surgical components of treatment, has been myopic in engaging with and healing the critically ill patient as an organic entity comprising not merely the body but a whole lot of other factors such as emotions, thoughts, and, above all, a supreme animating spirit.

Katie Couric's YouTube video titled "This Cancer Patient's Resilience During Covid-19 is So powerful", is about the breast cancer testimonial of Sarah Sanders, a resident of New York City, who was diagnosed with triple-negative breast cancer. Triple-negative breast cancer (TNBC) is a type of breast cancer in which the cancer cells tend to grow and spread faster into the area that surrounds the mammary tissues. It is very difficult to treat, as the progress of the cancer is highly unpredictable. This is because in TNBC the cancer cells do not have the three receptors, 0 estrogen, progesterone and HER2, and as a consequence there is uncontrollable division of the cells ("Triple-negative Breast Cancer").[13] The difficult prognosis of the disease made Sarah's condition especially unenviable when compared to that of other cancer patients because the nature of her cancer warranted constant clinical monitoring. In her testimonial, Sarah highlights the unique challenges faced by cancer patients during the pandemic. Sarah's comments in the video resonate with those of all cancer survivors.

Sarah Sanders had a tough time battling with cancer. Even more depressing was the news that she ran a high risk of contracting other types of cancer. At the beginning of the difficult journey, she had made it a point not to fall into an emotional outburst: "I didn't cry, I was just Like, Let's go" ("This Cancer Patient's Resilience" 1:34- 5:06). However, during the course of the treatment, her confidence was shattered by the unexpected twist caused by the pandemic. This could be understood through her expression of anguish, "and I broke, I collapsed" and "literally fell into my mother's hands" (1:47- 5:06). She was also depressed by the information that "you don't have an immune system to fight it off as well". She also expressed the sense of isolation she felt when Covid-19 restrictions banned the entry of bystanders. She says, "Nobody is allowed to come with you. No friends, no family" ("This Cancer Patient's Resilience"). The ups and downs she faced during the pandemic were far more than what she had ever dealt with.

It has been widely reported that one of the dilemmas experienced by both oncologists and cancer patients during Covid-19 was with respect to the advisability of vaccination. This dilemma was ideally resolved especially for the patients not exclusively through pharmacological wisdom but more congenially through compassionate counselling. The patients were apprehensive of the collateral damages by

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way of aggravating the cancer as a potential consequence of vaccination. Together with the restrictions placed on them in the name of social distancing and lockdown, the fear of the side effects of vaccination put the cancer patients under severe distress. Allaying such fears was a task that was not exclusively to be dealt with by medical science. The concept of medical humanities typically assumes major significance and scope under such circumstances. In the YouTube video "Covid-19 Vaccines for Cancer Patients: Medical Experts Answer Common Questions" uploaded by the MD Anderson Cancer Centre in Houston, the topic of Covid vaccination for cancer patients is addressed.[14] The video emphasizes the importance of receiving the vaccine as early as possible to elicit a strong immune response, despite the possibility of persisting side effects. It advises consulting the physicians to determine the optimal timing for vaccination. It should be noted in this context that it was the digital space which helped people and organizations to reach out to patients in need of aid and advice through their blogs and YouTube videos that proved more instrumental than the clinical space in dealing with the difficult scenario.

The Human Face of Suffering

The select cancer testimonials which are considered as illness narratives in the paper serve not only to better conceptualise the pain and suffering undergone by the cancer survivors but also to highlight as well as to devise alternate trajectories of disease management at the individual, institutional and social levels. All these narratives help to deconstruct the monolithic edifice comprising the doctor-medicine-patient triad that Western medical science had built itself into. Bill Gardner admits that he suffered from depression, which arose as part of the cancer treatment process, and acknowledges that it was predominantly the mental health campaigns undertaken by various agencies during the pandemic that helped him cope with his depression. This is quite normal for people suffering from cancer, as it brings them to the verge of their lives, forcing them to ponder upon death, pain and suffering. The telemedicine platforms, like 'Patient Support Line' instituted by the Ottawa hospital were not favored by him, as he couldn't digest the fact of a "phone robot" dealing with his illness reports (Gardner 4). Like any other human being who wishes to be compassionately taken care of in adversities, Bill Gardner also wished to have a holistic and organic therapy that allowed the physicians and patients to have empathetic face-to-face interactions. He also explains his feelings of burning sensation and the gradual pain and suffocation he had to bear during the administration of medicines. He found radiation therapy to be excruciating, as it destroyed his taste buds and developed blisters and ulcers, leading him to use a nasogastric feeding tube to consume food. He even dismisses the word "fight" from his pathological experience, as fighting to preserve life was not the same as fighting the disease. Owing to the pandemic, he was compelled to keep to routine hygiene protocols like sanitizing hands, wearing masks, face shields, gloves, etc. He describes the emotional cost of having cancer amid Covid as: "I'm now in the intersection of two high risk categories" (Gardner 10). Despite the Covid-19 cases increasing at a rapid pace, there were only a few people who were vaccinated. Gardner's remark, "Unfortunately, because of the pandemic, we're seeing a huge drop off in mammograms, colonoscopies, just routine visits to the PCP, digital related exams, and all of this stuff", speaks volumes about the frustration, anxiety and emotional burden that people who were otherwise critically ill felt, during the pandemic (Gardner 10). All of them needed much more than the severely truncated human and material resources that medical science could offer them.

Loriana Hernandez also points to the drastic dislocation experienced by the cancer patients as she gives expression to her anguish: "I was saying it's triggering a lot of post -traumatic stress disorder for me" ("Battling Cancer amid COVID-19" 0:30-5: 52). She reveals that the cancer patients were forced to accept frequent rescheduling of appointments and procedures during the pandemic since pandemic-related hospitalisation was given topmost priority at the time. This situation left many cancer patients torn between deciding whether to proceed with their regular checkups or to succumb to their fate and instilled in them the feeling of getting sidelined and isolated. Such thoughts often made Ms. Hernandez ponders death almost every day. Her constant thought was, "stare death in the face and lose friends" ("Battling Cancer amid COVID-19" 2:06-5: 52). Her overwhelming thoughts and fears stand vindicated by what 'ABC News' has reported her to be: "a five- year leukaemia survivor with a bone marrow transplant who doesn't have her own DNA" ("Battling Cancer amid COVID-19" 1:16- 5:52). During the pandemic the 'wound care nurse' had to visit her every day to dress the sores and blisters. This also made her apprehensive of contracting Covid, thereby increasing her level of anxiety. In order to preempt the visits, she asked her husband to learn the dressing procedure from the nurse, in order to avoid contact with outsiders. She found it very difficult to explain her feelings and concerns even to her own friends, as most of them felt consternation over her decision not to let them come to her doorstep. At a later stage it was revealed that she was suffering from depression. She felt that death was indeed waiting to snatch her. What sustained her through this phase of depression, as she herself reveals, was her love for her son. who was one year and a half old. The driving force that helped her to maintain her poise through the excruciating pain of the treatment was the intense desire to see her son live his life to the fullest.

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Covid-19 and the Recuperative Journey of Cancer Patients

Even as the pivotal role played by the medical and pharmaceutical sciences in the battle against cancer stands acknowledged, the world is gradually moving to a greater recognition of certain intrinsic and extrinsic factors that constitute an important part of the disease management system. The mental fortitude of the patient, as founded on his/her personal systems of belief and faith, motives and missions in life, attachment and commitments to specific individuals, professional goals and passions etc., constitutes the most important intrinsic aspect that reinforces the defense against cancer. External support by way of compassionate listening on the part of friends, relatives and well-wishers, voluntary service offered by palliative care agencies, an altruistic socio-legal establishment that ensures the best possible treatment for the poorest of the poor, and a liberal medical environment that promotes holistic and multidisciplinary treatment protocols and accords a participatory role for the patient in deciding on the best course of treatment also tend to be crucial in deciding the success of the therapy. Bill Gardner drew strength from his religious life as a Christian. The Bible verses were a relief to him, and he trusted in Jesus. He even acknowledges gaining inspiration from Buddhist thoughts, though at times he felt "I cannot get the care I need" (Gardner 15). He was seized of the seriousness of cancer at the death of his close friend, who died of ovarian cancer. Gardner remarks:

She maintained her energy, dignity, and hospitality throughout the years of her illness. Part of her secret for thriving despite surgeries and chemotherapy was staying fit and upright through long daily walks with her friends and a standard poodle, which she logged on her Fitbit. Witnessing her exemplary life helped prepare us for my cancer.[14]

This reveals how tremendous an impact the experiences of a cancer patient/survivor could have on a person who has just been detected with cancer. He argues that he does not 'fight cancer' and says, "My job is to stay mobile, attend to my daily needs, care for those I love, write a bit, and prevent depression. Fitness is a means to those ends" (Gardner 14). Gardner's own narrative regarding his illness maintains a quality that can earn it the status of a beacon light that can help other cancer patients to stay on the right course. His treatment regime included radiation, scans, follow up PET scan (Positron Emission Tomography), chemotherapy, biopsy and immunotherapy. He describes the intensity of the treatment in the following lines: "Of diagnostic procedures and their uncertainties, there is no end" (Gardner 14). A mental health campaign was held, which helped him to cope with the depression that he suffered, which arose from his cancer related treatment and illness. The physicians also steered clear the queries regarding whether the cancer patients could get vaccinated against Covid. They assured the patients with the statement, "The answer is always yes" ("Covid-19 and Cancer" 11:15-12:32). His personal experience of cancer turned out to be a transformative encounter. Gardner clearly explains the fact that "writing about this experience is helping me get through it".[10] Thus, sharing the experience of suffering was indeed a healing process for him.

For Loriana Hernandez, the "telemedicine appointment" ("Battling Cancer amid COVID-19" 4:50- 5: 52), was indeed a relief. It made her observe her own symptoms, progression or regression. The 'face time' she had with her oncologist gave her insights into many unknown facts about cancer and cleared all her queries related to the treatment process. Despite the treacherous treatments she had to undergo, she still maintained hope, and believed hope was a thing with feathers. Prepare, present and prevail was the advice she longed to give others to arm up for life.

For Sarah Sanders, her mother was the strongest source of support and confidence. Sanders says, "She'll always be that kind of pinnacle of strength for me," and she reminisces that her mother even played cards with her to help her to find every way possible to stay happy ("This Cancer Patient's Resilience" 3:49- 5:07). Sarah's mother could be said to have played a role as significant as that of the doctors and the hospital staff in her battle against cancer by the merit of the way she helped Sarah attain a well- developed self-concept, which infused in her a positive outlook towards life. On the strength of this reinforced self-concept, Sarah was able to cope with the restrictions imposed during the pandemic and to appreciate whatever possible care and comfort that an already stretched healthcare system was able to offer. Instead of remaining grumpy about the severely curtailed services, she remarks, "Healthcare workers are our heroes every day" ("This Cancer Patient's Resilience" 3:10- 5:06). She is seen empathetically reflecting upon the work pressure of the healthcare professionals and the time they had to spend with their patients, leaving aside their own families. "They'll talk to you like a human, not as a cancer patient. And my God, isn't that a welcoming and beautiful moment?" ("This Cancer Patient's Resilience" 3:34- 5:06). These words reflect Sarah's perspective on healthcare workers as individuals with a human essence. The video shows Sarah reminding herself to be grateful to her God for giving her a life to live to the fullest, which proves the most vociferous testimonial to the fact that healing is not just the administration of medicines but nurturing in the individual a love for life.

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Recommendations

The Covid-19 pandemic brought about significant disruptions in the diagnosis, treatment, and ongoing care of cancer patients and survivors. To address such challenges in the future, several significant measures can be considered. To begin with, the augmentation of telemedicine services which can facilitate remote consultations and monitoring for cancer patients, will reduce their risk of exposure to Covid-19, and ensure continuity of care. Additionally, strategies to organise uninterrupted cancer screening programmes and enhanced access to diagnostic services are crucial for timely diagnosis and treatment initiation. Collaboration among healthcare providers, cancer centers, and public health agencies are essential for a coordinated response to the pandemic's impact on cancer care. Also, providing the necessary psychosocial support to patients as well as the healthcare providers can alleviate the physiological and psychological trauma faced by both parties. To conclude, implementing these recommendations can help the medical establishment to deal with the dreaded disease of cancer during pandemics of such devastating nature in the future.

Conclusion

The Covid-19 pandemic added further strain on the already complex illness experience of cancer patients. In this context, narratives of cancer survivors provide valuable insights into their illness experiences, highlighting the need for compassionate communication between the physicians and the patients, and among patients themselves. Compassionate communication not only strengthens the physician-patient relationship but also promotes psychological well-being and resilience within the cancer community. Open conversations among patients, carers, and healthcare providers proved quintessentially functional in addressing the challenges posed by the Covid-19 pandemic to the cancer community. These open exchanges were also seen to go a long way in ensuring that individuals affected by cancer received the care and support they needed during those unprecedented events. In the webinar titled "Covid-19 and Cancer: Managing Stress, Anxiety and Grief during Uncertain Times" hosted by the National Coalition for Cancer Survivorship, a non-profit organisation in the USA, Dr. L. Imani Price, who is a licensed psychologist at Women's Inner Fitness and Wellness Center, LLC Washington, suggested that cancer survivors experience anxiety, stress, and post-traumatic stress disorder, from the new expectations and restrictions resulting from the COVID-19 pandemic, leading to feelings of helplessness and inability to control one's life.[15] Cancer patients, by sharing their experiences, can reflect on their journey, and thereby empower themselves and be an inspiration for others. Against the backdrop of the dislocations caused by the pandemic it can convincingly be argued that by engaging with patients' stories, healthcare providers can better understand their experiences and build more empathetic and compassionate care. Despite the global restrictions placed by the pandemic, it is essential for healthcare providers to engage in empathetic and transparent communication to address the fears and uncertainties faced by the critically ill. By fostering open dialogue, patients can voice their concerns, express their needs, and actively participate in decisions about their treatment. The need of the hour is to prepare the grounds for a greater emphasis on the psychosocial aspects of medical practice, and the need for healthcare providers to engage with patients as whole persons, rather than just as medical cases.

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