

'Thick description' of Graphic truths with ethno-graphy: a story of ALK- positive

Santosh D.Kale

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Concordia University
School of Graduate Studies

This is to certify that the thesis prepared

By: Santosh D. Kale

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Signed by the final Examining Committee:

Dr. Pippin Barr Examiner

Dr. Jonathan Lessard Examiner

Dr. Rilla Khaled Supervisor

Approved by

Dr. Martin Racine, Graduate Program Director

December 5, 2024

Annie Gérin, Dean, Faculty of Fine Arts

Abstract

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Santosh D. Kale

Cancer is a condition commonly known as a “life snatcher”. It is frequently assumed that cancer is more likely to affect those with weak bodies and unhealthy lifestyles, as well as older individuals. These and other incorrect assumptions about cancer significantly impact on the experience of a cancer diagnosis. On receiving an ALK-positive cancer diagnosis, I turned to the internet for further information. While some of the content that is available online is accurate, it is often low-resolution, and in some instances, factually incorrect or misleading. The quality of accessible information about cancer impacts on the lives of patients, medical professionals, and caregivers alike. From this understanding, three questions emerged from the study and personal experience: (1) Why is online information about health conditions so generic, and what do researchers acknowledge about the shortcomings of publicly accessible content? (2) What observations can I make by analyzing a handful of websites? (3) Can creating content/ story/ information through “thick description” using ethno-graphy help consolidate an understanding of ALK-positive?

Having experienced the quality of accessible information and with literature review, it was evident that healthcare content needs to be relooked. As a patient, I reflected upon myself and reasoned a way of bringing the experience as research- creation. It is an autoethnography that maps various events in the journey of being a patient in the form of ethno-graphy. The narrative is not centered only around the condition but there are several aspects that are interconnected with each other. It is a cluster of coordination between various systems or groups of professionals who became a part of the day-to-day life to keep the disease monitored. Chapter 1 shows the life around me gradually transcending to a diagnosis that needed further investigation. Chapter 2 and Chapter 3 are not in the scope of the thesis. These two chapters cover various systems coming together to put the condition into control. The thesis also breaks down the method of research-creation.

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Chapter 1: Introduction

My story begins in room 1945 on the 19th floor of the hospital. It offered a breathtaking view of the St. Lawrence River. Each day, the dark sky outside the large window transformed with the rising sun. Golden light painted the horizon, outshining the city's artificial streetlamps and the headlights that animated the river bridge, as commuters drove to and from their various shifts. This bright light entered the room through the Venetian blinds, painting stripes: I could feel the energizing warmth. Before their shifts ended, their exhaustion was clear, night duty nurses would greet me and check my vitals. Housekeeping would finish up, and the nurse support team would come to check on me. The nurses from the recent shift would place and store medicines on a small moving table. They would explain the dosage and leave, while another team set up the breakfast tray. It did not matter what there was for breakfast, as nothing tasted like food, but- I had to eat to recover my lost twenty kilograms, and gain energy.

The river occupied 40% of the window's field of view, flowing with ships, sailing boats, trawler boats, and windsurfers, each moving at its own pace. The people on the watercraft would dance freely on the river, and I would follow, looking at them until they were out of the frame. The river's activity was a great diversion from the hospital bed. Boats travelled in the river at specific times, departing from and returning to Montreal.

Before all of this, my life had a pattern. A typical day started with waking up at 5.00 am and walking the dog in Mile-End and the usual pattern would come after this starting point. Then, in sudden disruption, I was in the hospital. I received the devastating news that I had a form of cancer, and that it had progressed to stage IV, meaning that it had metastasized. My life started to freefall.

I recall a Zen comic strip of a man in mid-fall from a vertical cliff. As he stretches his arm as though seeking a handhold, his fingers instead brush against a ripe berry, and he plucks it from the vine and tosses it in his mouth. The story, uncaptioned, concludes thus, with the ending's interpretation left to the viewer.

The best way to truly immerse myself in my freefall was to document every detail of the experience, from the sights to the feelings. My Google search results were grim, predicting a vague life expectancy of less than a year. The information remained inconsistent, causing confusion that made it hard to accept even information which seemed well-formulated. I brushed off my despair and redirected my attention towards documenting the profound journey of being diagnosed with the condition.

A key breakthrough moment occurred when I learned I had gene markers for ALK-positive. Until that point, given that my cancer was at stage IV, my chances of survival were considered extremely low. The oncologist couldn't wait to relay this news

to me: she leapt from her chair and slammed her hand on the table twice as she confidently announced the ALK-positive status. I would begin taking a pill every day as part of a streamlined treatment process specific to ALK-positive. With the presence of these gene markers and the medication, immunotherapy would be much more effective, as the body alone had to react to the medication.

To my surprise, I discovered the internet was severely limited in terms of providing further information on my condition. As a designer, this motivated me to share my experiences and learnings about ALK-positive through the lens of a person experiencing it firsthand.

Keywords:

ALK-positive, Design ethnography, semi-structured interviews, participatory design, autoethnography, ethno-graphy, thick description, system design, mediation, information, misinformation, disinformation

1.1. Background and context as a designer

Understanding the designer's journey is a vital prerequisite before delving into the details of the research-creation. As someone who is academically trained in communication design, and who has worked in the industry for twenty years, I've consistently witnessed change. Evolving understandings of problems and attendant

technological advancements have been instrumental in shaping solutions. Design as a profession has increasingly focused on problem-solving, as the journey continues, and each previous project has presented its own set of challenges.

I have experience developing video games, creating feature films, designing for broadcast, generating content for publications, and developing research-focused applications. Throughout this process, I have gained valuable tacit knowledge through personal growth and continuous adaptation to new challenges, which required me to master new tools and acquire new techniques. With the ability to create designs and the experience of working hands-on, I realized the importance of investing this knowledge in research-creation to understand how best they can be used to tackle real-world issues. Prior to delving further, it's vital to acknowledge the position of design in the larger research community. It became evident, through reading design research papers, that there is a lack of rigorous methods for designers to use in the research-creation process. Rather, we must adapt various methods from different scientific fields to achieve our goals.

The challenges are increasing due to the constant development of real-world problems. As conditions shift dynamically, the complexity of 'wicked problems' is becoming more entangled itself. In the "Dilemmas in General Theory of Planning", Horst Rittel and Melvin Webber call these problems malignant", "vicious", "tricky" and "aggressive" [2]. These problems cannot have definitive formulation, no stopping rules meaning the problem cannot end with a solution, even if there is solution it cannot be good or bad- true or false. It can generate waves of consequences with no room for trial and error. The solutions cannot be constructed based on previous solutions and each of these problems are unique. The problem can be expressed in different ways. All these put together makes the wicked problem incorrigible to address it using conventional scientific methods.

In his interview [3], Christopher Frayling addresses the inadequacy of scientific methods when faced with unorthodox problems. Science and design are not the same. The former examines the current state, while the latter addresses the future state. Designers use their vision to create artifacts that support their thoughts about the future state. Using a design approach allows us to sidestep some of these limitations and address the core issues [4].

In 2019, just before the pandemic, I was employed at Microsoft Research in Bangalore, India, where I met different researchers focused on ‘technology in emerging markets’. It was here that I first became involved in an interdisciplinary collaboration between ethnographers, computer scientists, and medical professionals. That allowed me to observe how design can play a role in the research environment. The word “research” is commonly used by designers, but without much depth: I realized this when I noticed that people of other disciplines had set practices and methodologies to draw from in undertaking research. My role, however, became a ‘bolt-on’ to other research processes that Frayling covers in his work.

Frayling believes that design should be equally valued, relative to the scientific method, in the research process, whereas collaborative research does not give it the same level of importance. This perspective called me to identify the specific areas where the role of design takes center stage in research. Recognizing that other disciplines depend on design intervention, it becomes clear that understanding ‘wicked problems’ is vital, and so I began to look at real-world problems by crossing over from working in the industry- to understanding various methods like semi-structured interviews, ethnography, and participatory design.

The development of applications for underprivileged individuals, mental health, accessibility, and hospitals helped me understand the concept of 'research through design'. While readily available technology rendered the application-development process nearly effortless, a process of assembling software libraries, I noticed a lack of thorough user research during the design process of certain applications, and they failed to capture knowledge of their stories. Recognizing the gap, my aim as a designer was to capture the intricate stories of people, rooting my process in human-centred design, which relies on the concept of empathy. The design has to be derived from the feelings, thoughts, and perspectives of end-users. For this, the lived experiences of users must be understood in depth, necessitating extensive research into their aspirations, needs and challenges. [5]. Gathering detailed stories ultimately leads to human-centred design. My focus at this moment was on the former rather than the latter.

Making detailed stories accessible, with the hopes of promoting dialogue among people in communities worldwide, was another goal which informed the process of gathering them. I realized that allowing conversations to flow freely enables the formation of more elaborate stories. W.Mills touches on this in the "Sociological Imagination" - noting that "individuals can understand their experiences and realize their situations in life only by being aware of the other individuals who are in the same circumstances."

With these mental concepts already figured out, the plan was to implement them in the MDes program. The starting point was to gather a list of people who could be interviewed during the summer of 2022 for directed studies. After finding the right participants, semi-structured interviews were conducted as per the guidelines of Steinar Kvale (1996) in “An Introduction to qualitative research interviewing”.

These conversations were converted to text as scripts for creating ethno-graphy. a hybrid of the word and visual combination telling real stories that fall in the category of comics and graphic novels. The process of developing the series of visuals in a sequential order was to work collaboratively using participatory design. Where I would go back-and-forth with dialogue, while creating a detailed story of their lived experiences. By the end of the directed studies, there was a clear structure for compiling an anthology of stories- from research to research-creation .

By this time, all the preparations were in place for the full-fledged work to begin on the MDes research-creation, but it was at this moment that I experienced a sudden dramatic change in my circumstances.

1.2. A change in direction triggered by a change in health

I began experiencing breathing difficulties, which were initially misdiagnosed as seasonal allergies that were difficult to manage. However, a lack of improvement in my condition necessitated further investigation, including X-rays and a CT scan.

After finding lesions in my lung and rib, the doctor told me that my life would never be the same. Additional examinations were necessary, and a biopsy was taken. While I waited for it to be analyzed, and lacking official confirmation of my status, I went online and, driven by curiosity, searched “lesions in lung and bone” in the hopes of better comprehending the doctor’s words.

It was frustrating to see internet search results had different answers. I did not get anything out of it, instead it further confused me. Clicking a single link would lead to a chain of other links and eventually I would discover that the initial search query had since moved away to other health conditions. Attempting to void my mind of the irrelevant material I had just encountered became another problem in itself.

Within fifteen days of the biopsy, I received confirmation of my metastatic cancer. A while later, I developed a high fever, which resulted in hospitalization for severe pneumonia. As someone who had looked after his health throughout his life, and regularly walked seven to eight kilometers daily without fatigue, I recognized the gravity of the situation: my body had deteriorated and left me vulnerable to disease, despite my healthy lifestyle.

I learned that the growth in the right lung blocked the bronchi, trapping the infection. To open the passage and clear the infection, the doctors used a stent. They confirmed that the cancer had an ALK-positive gene profile. A session with an oncologist offered valuable insights, yet I was overwhelmed and didn't understand some of what they told me. My family medical history did not feature verified instances of cancer, and the experience of being a first-time patient with a major condition was overwhelming, frightening, intense and difficult: I had many questions, as did my family, but I only ever had a short time with my doctor. What sets vital questions from trivial ones? It's hard to differentiate both in such circumstances.

Cancer diagnosis leads to an unforeseen journey, and patients often seek insights from those with lived experiences to understand their own future challenges. So again, I turned to the internet for information. Some websites were endorsed by medical bodies, while others were unverified. Acquiring knowledge was time-consuming, and I noticed that “reliable”, professionally endorsed websites lacked comprehensive experiential details. As a patient myself, I wanted to learn more about the experiences of other patients with the ALK-positive condition.

The purpose of using basic and generic language for online information was to provide an accessible summary of the condition. For similar reasons, the websites had segregated information presented in discrete sections, and stories were lacking or absent entirely. Patients in carefully edited short films discussed their conditions, but their narratives fell short of information. The films were motivational but incomplete.

After accessing the online information, I turned to the literature review to understand the reason for the current state. Below is what was discovered after doing a series of literature reviews.

1.3. The current state of health-oriented online content and social media

Misinformation and disinformation on social media

Misinformation is gaining traction because of the influence of the information system, distracting from critical public health concerns. [10,69]. Malicious false information on social media diverts attention from core systemic problems instead of promoting communication and accurate information exchange. [10]

With the increasing prevalence of misinformation, fact-checking efforts are becoming more complicated. Whether an individual is able to isolate specific claims and verify their accuracy depends on the extent of their exposure to the dynamics of information flow, and the impact of those dynamics on the public health system. Various factors influence the ambiguity of online content, such as authorship and site exposure. Correcting misinformation requires more than tracking down inaccurate claims and countering [9]. There are no inherent limitations on the kind of information that is generated and shared in the emergent system of social media.

There are also few regulatory controls protecting social media as a democratic space with the right to free speech. This leads to the worst of both worlds, a space

allowing for the dissemination of incomplete, misleading, or false content, but without protections of the freedom of speech of the producers [9].

Moreover, the interplay between the constant iteration of novel treatments and the patients' constant search for information on the internet, make communication dynamics in the context of medical information a fast-moving science that is difficult to keep pace with. There is a correlation between lower quality information and the receipt of 'thumbs up' feedback in social media like Facebook, Pinterest, Reddit Twitter, WhatsApp, TikTok [10] and YouTube, and false information is more widely consumed than scientific quality information [10]. The adaptability of new media platforms allows for constant changes to content algorithms and data privacy policies, which can complicate the patterns of information exposure for individuals. For example, flagging options have been added to these platforms, but the outcomes are unclear, given social media's ever-changing content. Misinformation and disinformation could lead to harmful actions, interactions, and inaction [10]. Patients tend to look for easy and understandable information, without fact-checking, and their critical reasoning skills may also be impacted as they undergo treatment that causes cognitive impairment due to side effects [10].

The key in addressing these problems is to tackle the systemic conditions that foster the dissemination and adaptation of misinformation, instead of solely investigating individual instances of misleading content. When money and exploitation become a part of the information, things take another shape of disinformation.

Disinformation for profit

The prevalence of misinformation and disinformation can be attributed to the profitable market represented by patients searching for miracle cures or preventive treatments. By intentionally spreading inaccurate information, they take advantage of patients' desperation, and their attendant willingness to spend money on alternative remedies, cancer recipes, books, coaching, and institutes [10]. To create the appearance of authenticity, predatory journals are established to publish research papers that produce scientific productivity metrics, which are then used to produce content that seems to satisfy those metrics [10]. These papers have been used as references [10] by legitimate scientists in ways that strengthen the perceived credibility of alternative therapy products. This deepens the vulnerability of patients, as the information is jumbled beyond the ability to segregate facts from fiction [10].

Legal actions cannot be taken to stop pseudoscientific beliefs, as “cancer” is a generic term for a complex condition that manifests as hundreds of distinct diseases, with innumerable treatment options [10]. In-depth knowledge of one cancer doesn’t equate to an understanding of all other cancers. The legitimacy of online information is unknowable, unless it is scrutinized by medical professionals, which is bound to never happen if it is online content. Apart from these intended and unintended manipulations, the information can be authentic and factual but it falls short of the purpose because of the resolution. This will be discussed further.

Low-resolution quality of information accessible to general masses

While healthcare education materials are easily accessible online, they are of no use to the intended audience if the content is too complex. Readability is linked to the literacy levels of the general population. The material has to be simple, and the National Institute of Health (NIH) and the American Medical Association (AMA) recommend that the content must be written for 3rd to 7th grade and not above the 8th grade [12, 8, 13]. With an average of 12.6 grades, the information level becomes challenging to grasp and loses its effectiveness. There is a correlation between difficulty in comprehending information and cancer risk and severity [12].

There is misinformation, disinformation and low-resolution information that various scholars have identified as the reason. Having content online has various advantages, and there is a necessity for information that touches the needs of the patients.

Need for authentic content

The internet is experiencing a significant surge in traffic related to lung cancer, highlighting the need for caregivers and patients to access reliable and supplementary information. [14]. Although there are limitations on contact time with physicians, they make every effort to give detailed information to patients and caregivers, but the daily experience of the health condition brings forth unforeseen inquiries. Patients need to learn about follow-up diagnostic examinations, procedures, visits, and therapies that are often subject to patient cost sharing in the form of deductibles and copayments, in addition to the potential costs of travel, missed work, and similar expenditures [13], which the doctors can support with what is within their scope. However, due to the limited bandwidth that health care practitioners possess, it is important for medical professionals to acknowledge that patients expect information online. It would be beneficial to compile a list of content that effectively communicates the patients' condition. Doctors are under pressure to provide reliable online information [11].

Reading the literature aligned with the impression I got from the experience of the online content. The next step was to take this experience and observe the websites from the lens of a designer.

1.4. Self-analysis of the online content (detail breakdown in appendix)

Various authentic websites were analyzed, from content to user experience, and I reflected upon them from my perspective as a user/patient who is seeking information about a specific condition.

Below is the holistic summary of various websites, and the details of the analysis can be found in the Appendix section at the end of the document.

Quebec Cancer Foundation. Montreal. 2024. Available from:

<https://cancerquebec.ca/>

Canadian Cancer Society. 2024. Available from:

<https://cancer.ca/>

Wikipedia. 2024. Available from:

https://en.wikipedia.org/wiki/ALK_positive_lung_cancer

ALK Positive. Atlanta, GA. Available from:

<https://www.alkpositive.org/>

American Cancer Society. 2024. Available from:

<https://www.cancer.net/>

The public struggles to understand the medical terminology on these websites. Medical terminology is vital in the communication of complex medical information, but counterproductive if the public can't comprehend it, negatively affecting information interpretation. Narratives and examples provide context for understanding medical terms. There's an inconsistency within the websites that bothered me as a reader: certain sections are complex, while others are basic and lack specifics. It's like reading one article with different writing styles from multiple authors. Websites are often outdated, unlike the rapidly developing field of medicine.

Problems include the lack of interlinking between sections and the absence of captivating factors for winning reader engagement. Researchers have shown that the general public find health-centric social media content appealing [11]. The contents in these platforms are designed with the intention of captivating audiences with concise, non-scientific messages. Interesting content increases believability. Yet, fact-based information from reliable websites tends not to demonstrate these characteristics.

Having analyzed various online content sources, and information gathered from the literature review, the objective of my research-creation project became to create easily digestible content that minimizes the weight of text, through the use of

ethno-graphy – a subset of visual ethnography that has its roots in ethnography. Combining words and visuals, the aim became to encapsulate information about ALK-positive as a descriptive journey. I set out to use autoethnographic with ‘thick description’- that is having a theoretical framework. With this framework, I wanted to capture my lived experience, building on the earlier process I had already established in conjunction with the use of semi-structured interviews and participatory design.

1.5. Theoretical framework

'Thick description' is the interpretation of culture that has a methodology of robust ethnography and intellectual implications of the approach. Details of everything and everyone can be purposefully and meaningfully observed and documented, indicating thickness [23]

Schwandt says that thick description is not about amassing relevant details. It is a social action of interpreting the recordings of circumstances, meanings, intentions, strategies, motivation- with the characterization of a particular episode. It is the characteristics of the description rather than details [23]

Holloway talks about it as a description that brings the sense of emotion, thoughts, and perception that participants experience. It is not about interpreting the meaning of people in culture, but with intentions [23]

According to Geertz, 'thick description' can be compared to tree roots that nourish 'thick interpretation' in a similar way that the solid trunk of a tree feeds on the branches and leaves, representing 'thick meaning' [16,15]. Geometric metaphors [17] are common in the anthropological language while documenting, which adds ekphrastic [17]

Different fields may have different interpretations of the term 'thick description', but its core principles and characteristics are clearly defined. 'Thick description' should promote a 'thick interpretation' of the actions of the researchers, which creates "thick meaning" that engages the readers by giving them a clear picture of the research material. The qualitative interviews should capture the lived experiences of the participants to get the same interpretative conclusions as the researcher [18]. Thick description should include commentary, interpretations of that commentary, with 'microscopic' detailing of social settings made available to a wide audience of readers [18]. The readers should experience the verisimilitude of what the researchers have experienced during the process of observing and documenting--which is not restricted to present analysis and is inclusive of future intentionality [19].

The concept of "thick description" is used in various disciplines for qualitative research, such as education, sociology, psychology, program evaluation, and inquiry methods like phenomenology, grounded theory, and case study [15]. Balancing

understanding and practice of this term proves challenging for researchers and students in their respective areas of research [15]. Gilbert Ryle, a British metaphysical philosopher [16], used the term “thick” description in a series of lectures published in 1960 under the title “Thinking and Reflecting and The Thinking of Thoughts: What is “La Penseur” Doing?” [15].

Geertz (1973) introduces the term ‘thick description’ to anthropology, and Denzin (1989) expands its application to Communication, Sociology, and Humanities [15]. Holloway (1997) and Schwandt (2001) provide further elaboration on this term. All of them speak with the same essence, but have changed the application of the term, based on their areas of research, Ponterotto [15] consolidates all their ideas and clarifies the differences and meaning of this term.

Even if ‘Thick description’ is well-defined by various scholars, it has constraints of describing it with words.

Limitations with the written description

Geertz emphasizes the need to be aware of the sensory dimensions of experience. Experimenting with the body and senses while researching, rather than only focusing on writing styles [16, 15, 20] he found problems associated with textualization (written documentation). The researcher's objective observation of the subjects is compromised by these problems. According to Sopranzetti [21], words fail to fully capture the reader's experience of the city's smell, the heat of concrete, and the disorientation produced while in traffic, identifying limitations to describing "the materiality of spaces" that the researcher could not overcome with words alone. This led to using various means to assist 'thick description'

The emergence of visual anthropology- 'thick description'

With the advancement of accessible technologies, researchers can now employ a range of media formats, including films, drawings, photographs, and sound recordings, to collect and retrieve detailed information. There is a growing awareness of the emergence of embodiment and sensory experiences. Visual ethnography combines visual and written elements to explore reflexive dimensions, and new approaches, utilizing theoretical grounding, hypermedia, and a mix of visual forms like photography, video, and drawings have transformed the practice [22,20]. These new approaches diminish researchers' personal perspectives and portrayals as sources for fieldwork.

By capturing heartfelt emotions, ethnographic films provide researchers with a multi-dimensional perspective on events, facilitating a deeper comprehension of people's essences. This has given rise to new ways of ethnographic writing [20] that bring character to the studies. [20] Not accepting visuals in this area is a thing of the past [20].

The focus of visual ethnography has shifted from the broader understanding of ethnography as traditionally approached by mainstream anthropology [20], adopting a methodology that involves analyzing human experiences through a combination of visuals, writings, and other sensory experiences such as hypermedia, leading to the emergence of real-world applications. This can transform beyond the scope of the academy and act as a conduit of communicating to the audience in an effective way [20].

Images have their own power and agency. Through visual representations, viewers can form their own interpretations of the construct and its meaning [24]. Just like ethnographic films, photography has been employed in fieldwork to record the diverse cultures and immersive experiences in foreign lands, especially during the later stages of colonization when cameras became accessible [25]. Still images, like

photographs, can create open-ended meaning for viewers, but captions can guide interpretation. [23]

The fundamental dimensions of image interpretation can be delineated into three categories: 1) the fundamental data the content represents, 2) the meaning that it communicates to the viewers, i.e.- the way they look at it and read it, and 3) the reactions of viewers [20]. The act of 'audiencing' refers to the process of analyzing a viewer's interpretation of the image [20]. The decoding of the visual reading and differing perceptions of the same images is a complex analytical process that developed through participatory design [20] As Pinney [23] says, "only film or video can record the realism of time and motion of the psychological reality of varieties of interpersonal relations."

With many advantages of using visuals with words emerged the word visual combination of graphic truths.

***Vérités graphiques* in ethnography**

A concept I chose to center in my research-creation is *vérités graphiques*, or "graphic truths," in the format of graphic novel, though I remained open to multiple approaches to utilizing visuals, sounds, and words. "Ethno-graphy" as an experimental form resides at the convergence point of different design areas but is a bifurcation from visual

ethnography. *Vérités graphiques* [26] is subjective, self-reflective, and interactive, offering narrative potency, gaining popularity, and fostering the 'sociological imagination'. By using illustrations, anthropological concepts become vibrant and animated [27]. Drawing as documentation during fieldwork is a common practice by researchers, but this form involves building the narrative through sequential visuals for documentation, in a symbiotic relationship with the words [43].

The 'gutter' (Image. 58) is the unique characteristic of sequential art. The in panels is where the action takes place, the gutter in-between the panels serve as a transition that bridges time, scenes and action [28]. The speech bubble are limited words in the blob that helps the reader to give sufficient information to connect one image to the other. The various images can be in a sequential order, or it can have jumps. The binding factor for the images are the speech bubbles and consistency of the imagery that enable the reader to comprehend.

This format is "Verbal-visual interdependence" [29] simplifies the transition between images, words, and visual icons [28], reducing unwanted details and making the format accessible to a wider audience [27]. The pedagogical task is to merge the world of research into this format [11].

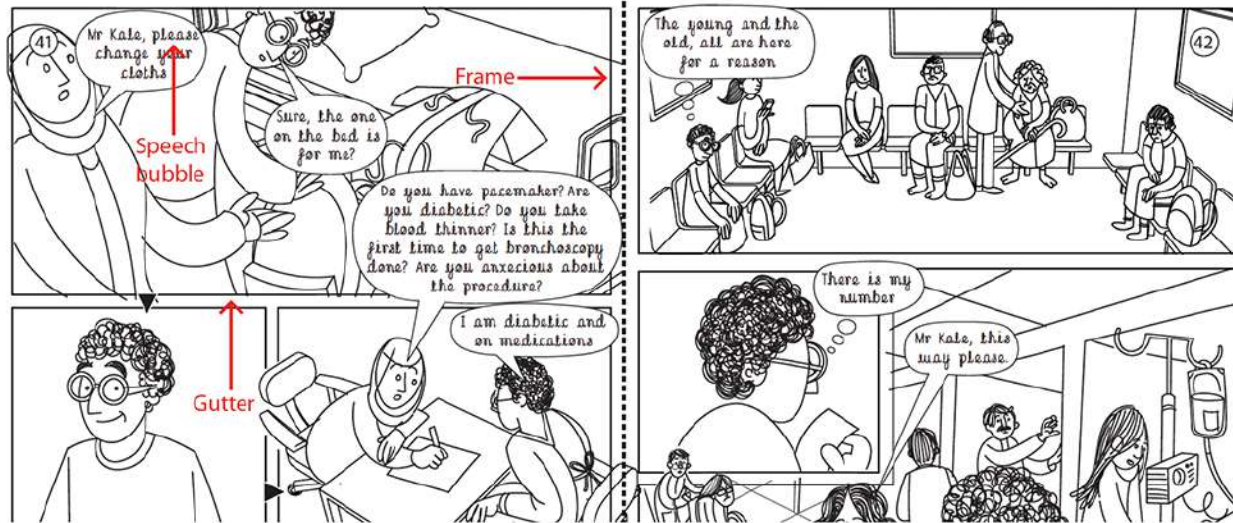


Image.36

Sequential with ethnography

Jeff Adam says to bring the “narratives of the past [are] within the present” [30]. The process of documentation for ethno-graphy supports the way fieldwork is conducted to touch upon sensitive areas of research, where participants can give their feedback [29]. It is a collaborative process that requires the unique skill, dedication and know-how of working together with multiple teams and participants together [30]. Ethno-graphy requires a division of labor between writers, scriptwriters, editors and visual designers, all fields involving production- through collaboration [29]. It is a dialogical process where participants are an integral part of the development, communication, and feedback loops. Structuring the research this way reduces the power dynamics between the researcher and the researcher [29]. In this piece of research-creation, however, I opted to handle all of the stages on my own.

Ethno-graphy is versatile in communicating any kind of research, and below are some of the broad topics that have been covered.

Applications of Ethno-graphy

Ethno-graphy has been used to bring various forms of qualitative research to life, including: what is actually involved in Electroconvulsive therapy (ECT) [44], child-centric perspectives on environmental injustice [45], self-care and collective care in terms of mental health resources [46], family histories of displacement and immigration [47], and the lived experience of dwarfism [48].

Comics, too, have been used in a wide range of educational and public service contexts. Mathematically themed graphic novels have been created to provide insights into mathematical concepts [52]. The intersection of liberation and speculation are reflected in Afrofuturism comics [53]. Employment contracts as comics have been created for to maximize the clarity of communication of employment relationships, while respecting compliancy with Danish and EU labor laws [54]. Anglo-Australian contract laws have been visualized as comic contracts, sparking a debate on whether this format is legally valid, and ultimately these comic contracts stood the legal test [58]. The quest for identity in the minority group in the United States has been captured in comics [55]. The trauma of the second Intifada and the existential fear of annihilation has also

captured in a graphic novel [56]. Even the American recession of 1990 has been subject matter for comics, in the form of graphic narratives about ordinary people who cannot succeed under capitalism [57]. In the health arena specifically, the 2020 global pandemic resulted in a large number of “pandemic cartoons” in response to the hashtag #DrawTheCoronaVirus [50]. Comic strips with information were used as pedagogical tools for teaching about illness and illness politics during the first year of the pandemic, by showing graphically depicted medicine in action [51]. The possibilities of ethno-graphy in comic/graphic novel form are unlimited: they facilitate humanistic engagement on topics that are complex to understand, and they can make mundane information easy and enjoyable to comprehend.

With all these references of research material covering various subject matter and different styles of execution, I began the research- creation.

Chapter 2: Objective of the research-creation

Using ethno-graphy, I set out to share my personal account of discovering I had ALK-positive as well as the treatment experience that followed my diagnosis. 90% of patients with this cancer variant discover their condition when the condition has reached stage IV. Without proper precautions, survival is typically limited to twelve months, but as of today, the median time of survival is six years with appropriate medication [59].

Websites that are endorsed by medical professionals provide ample information about ALK-positive, and patients have shared their experiences through short films and surveys. Online, one can even find support groups that provide answers tailored to one's specific situation. But as a patient seeking information about the condition, what I found to be lacking was a coherent narrative that put all of these pieces together while maintaining the richness of detail of a personal account.

To tell the story in a 'thick description', it had to begin with assembling blocks of information documented in various forms to plan the structure of the narrative.

2.1. Narrative arc

The book titled "1945" named after the room I was admitted to on the 19th floor of Endocrinology division at CHUM, is comprised of three chapters: chapter one covers the discovery, chapter two focuses on the experience, and chapter three explores the force of various systems within the university, government, non-government and the hospital- working together. At the time of writing, I have created the first chapter, which covers the early stages of testing preceding the official cancer diagnosis. This thesis primarily addresses this first chapter, but the shape of the overall narrative has already been planned.

The second chapter deals with my month-long admission to the hospital for pneumonia because of the growth in my lung, and the third is about various systems (support groups) working together to help control the disease.

The story's resolution addresses my personal journey within various systems, a narrative that is specific to my situation as an international student receiving support from Centre Hospitalier de l'Université de Montréal (CHUM), Montréal, Canada. Not every part of the story will resonate with every reader, but the goal is to provide a holistic view of the experience to which all readers can relate to at least some parts. The idea is to create more stories of other individuals in the future and gradually engage various members in the system- the hospital, support groups, faculty, family, pharmacy, the international student office and the insurance company should all form part of the research enquiry.

The story can be a personal experience, but a combination of search methods was used that differentiates from narrating the story as a self-expression compared to research-creation.

2.2. Methods

The method used to create the graphic novel is autoethnography, rooted in Semi-Structured Interviews and Participatory Design, which will be explained further.

What is autoethnography?

To comprehend the meaning of autoethnography, it can be divided into three components: 'autós' representing personal experience, 'ethnos' representing cultural understanding, and 'graphia' representing writing or systematic analysis [61,62]. It combines elements of 'process' and 'product'. This method encourages deep self-reflection and self-examination. The latter is an inquiry through writing centering personal relevance, a unique experience, and the universe in the self [61, 62].

The words 'reflexivity' [61,63] refers to in-depth- self-reflection guided by care values, and relationships with others. It connects self-identity with research-based insight into layers of emotional, theoretical, social, political, and cultural praxis.

Although it is creative writing, it is not a memoir, nor autobiography, nor fiction. It uses concepts of character development, dialogue, action, description, settings and plot

development, rhythm, and pacing as tools guiding documentation. This nature of the work is to understand the meaning of struggle, what to do in the face of it, and how to live through it [63]. These can be sensitive topics, involving direct experiences of oppression, racism, cultural problems, loss, and illness that others have not experienced [63]. The intent is to make such experiences accessible to a larger audience outside of academic settings and to humanize research in engaging ways [62].

Does this method have rigor?

Scholars question the rigor of autoethnography. The fundamental critique of autoethnography revolves around whether researchers can rigorously engage with social and cultural phenomena through first-person reflections and memories. Critics argue that it is artful and not scientific, or vice versa [62]. Critics also raise questions about the amount of fieldwork autoethnographers undertake, as they only observe a few members of a culture, and do not invest time in others. Documenting solely about the experience of the self can lead to biased information. In the most pessimistic light, autoethnographers could be characterised as self-absorbed narcissists who are unconcerned with rigorously and responsibly producing academic knowledge. [62].

Autoethnography as an amalgamation of qualitative methods

Autoethnography is a method that disrupts the binary of art and science; it is a hybrid approach that draws on a wide variety of methodological concepts that are a part of qualitative inquiry to structure narratives about cultural phenomena [61]. These methods can engage sampling, data collection, data analysis, biases, interviews, participant observations, conversational engagement, focus groups, narrative analysis, artefact analysis, archival research, personal journaling, field notes, thematic analysis, context, interpretation, photo documentation, recordings and more. Researchers use a combination of these methods to present factual stories effectively [61, 63, 62, 64, 65]. Despite potential scrutiny on the rigor of autoethnography, diverse qualitative research methods form its foundation.

Being an autoethnographer

Researchers using this method believe the process is therapeutic, emotional, and rigorous [62]. The outcome should be aesthetically engaging and evocative, and should feature storytelling components, characters, thoughts, emotions, actions, scenes, and plot development. Autoethnography should bring to light new perspectives, finding and filling existing gaps. The written voice can be first person to effectively convey a personal narrative, second person to make the reader actively situate themselves in the scene, or third person to create a context to show report findings and present information.

Doing an autoethnography is possible only by borrowing various methods and to carry out research-creation of this nature was not possible without the experience of creating the pilot project.

2.3. Drawing inspiration from methods used in the pilot projects

The two earlier litmus test stories of ethno-graphy that were created based on semi-structured interviews and participatory design became the basis for the book titled “1945”. The processes that were derived through that initial practice, prior to my diagnosis, were incorporated and refined. I had to take on the dual role of researcher and participant and conduct a similar form of SSI. The goal was to have lived experiences, with context, and then to connect the dots of journaling and photo-documentation.

The process of execution followed the same steps of participatory design, with an execution that happened in three phases. Each phase concluded with a critical analysis of the development of the story, followed by changes intended to keep the story authentic, engaging and aesthetically appealing. As mentioned above, autoethnography is a qualitative method that draws inspiration from various methods to create its own kind. My ultimate hope was to mediate the awareness of ALK-positive, through my personal story of being diagnosed with this condition.

2.4. The step-by-step breakdown of the research-creation

The story of “1945” traces my life when faced with a sudden obstacle, and how I overcame mental and physical challenges. It could not have happened without the support of others (caregivers and family), or my personal willingness to fight to overcome the difficulty. This is the story of a life that unexpectedly underwent a drastic change, exploring the question of “why” it happened to someone who had a healthy and fulfilling life. This resulted in a graphic novel that narrated the journey in an entertaining and easy-to-understand manner, catering to both individuals with the condition and their caregivers.

The implementation of the research-creation can be divided into five stages 1) keywords 2) rough drawings, 3) refined drawings, 4) lighting 5) speech bubbles and script.

1. Development of keywords

Visuals and text are important to the graphic novel format, but which comes first in the creative process? Content creators working in this medium could start with visuals and then write a supporting script to complement them, or the visuals can follow the script. There are a wide range of creative processes pursued by solo creators and collaborative teams [67]. Hergé, a Belgian comic artist, shaped the story and the characters as he drew it, pursuing a hybrid strategy. [The Comics of Hergé When the

Lines Are Not So Clear]. Text can also limit the free process of visual ideation, constraining the potential of visualization. It's important not to assume that text is the starting point for the creative process [66]. Scriptwriters should be sensitive to the style of visualization pursued by visual directors, and the specific needs presented by the graphic novel format, in which the imagery comes first in the scriptwriting process. Writers have to visualize the story in their minds, which is true regardless of whether they are writing for a graphic novel.

With '1945', the starting point was recollecting experiences that were stored as photographic memory, supported by journaling, photographs and drawings. The process of developing the eye for observation- registering it as a photographic memory and using it as practice of self- reflection will be elaborated. I created short lines within the chapter, giving no thought to the visuals. I carried out the rearrangement of these lines to create a basic structure of the narrative for the chapter, composing the key moments into sequences using these short lines. The starting point for rendering a visualization began with the expansion of these "keywords" within the short lines of each chapter. After the completion of the entire sequence of the drawings, the script was added based on the resolution of the images, i.e. the level of accessible meaning each image conveys at first glance, without having to think about it. The script exists to complement the visuals where they need help in making complete sense. In content creation of lived experience, certain elements of text are irreplaceable by visuals,

possessing a unique power in communicating the idea. This process is ideal for balancing the strengths of words with visuals.

To summarize, the process started with words, and visuals were used to expand these keywords. After developing elaborate visuals in a sequential order, the script was developed.

2. Rough drawings with panels



Image.1

These take the basic structure of the text narrative and do quick representations of the idea. This process involves working iteratively to get the holistic feel of the entire sequence/ chapter. Here, it is not about perfecting things, but laying them out fast for quick visual feedback, flexing the mind. Until we possess a sense of the base structure, variations of rough drawings are created. The purpose of drawing minimal lines in this

process is to keep it simple, allowing for enhancements in later stages. This understanding depends on the experience gained through practice. Achieving clarity with lesser details is helpful in creating volumes, with the flexibility to alter the drawing and try out various possibilities. The more details there are, the more natural it is for the designer to become victim of the sunk cost fallacy, becoming rigid and accepting the direction, rather than exploring alternatives. Inflexibility to change is conducive to improvising the narrative.

3. Refined drawings



Image.2-

Refined

drawings

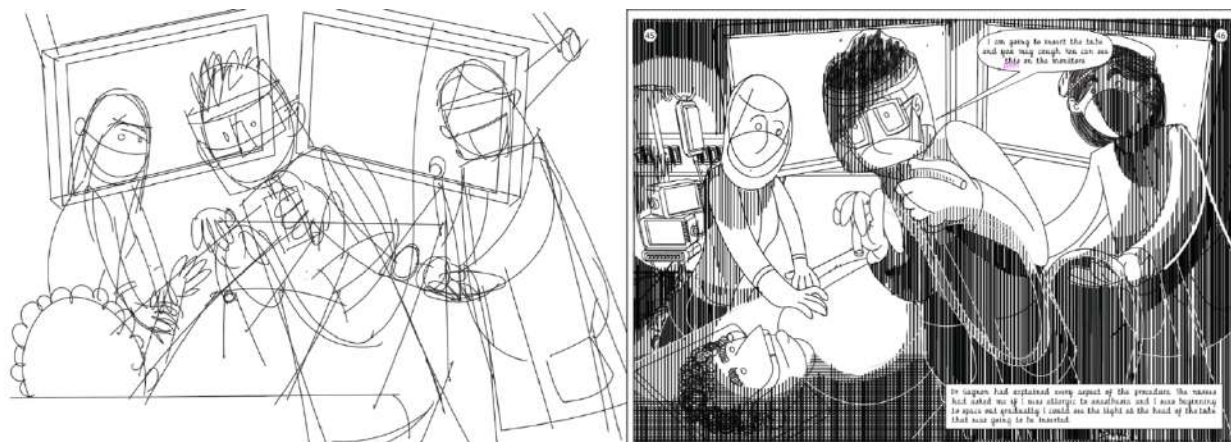


Image.3

At this stage, the rough drawing on the left (*Image.3*) of the frame are used as a base to convert them to refined drawings. These two images are the extreme endpoints of the process. The composition remains roughly the same as the content is developed. For example, the people (doctor and nurses) are carrying out the same actions, but the rough drawing shows the backside of the patient's head, and by the end of the process changes were made in order to capture the face. Although the face is expressionless, it shows the spaced-out condition after the anesthesia had affected the body. The patient's eyes are open, but from their point of view, the world appears blurred. Despite the lack of mention of these details in the script, the designers still need to pay attention to them. It is challenging to express these intricacies with lines because, they are the simplest form that can denote the shape of an object. Introducing emotions and conditions of the situation with lines comes from practice with using them in versatile and varied ways.

4. Lighting- mood and atmosphere



Image.4

The decision to create the sequences in black and white was deliberate. There is no justification that proves the superiority of using colors versus black and white. During my experience working on a project with UNESCO, researchers conducted a study in which they observed participants were more focused on the content and message of a black and white graphic novel, relative to the same content when presented with a few colors. Using colors can create a mood and atmosphere, which can be advantageous, but what would be the ideal way to create the same feeling?

A solution to this is to add hatches that create tonal variation. In the image below, (*Image.5*), the doctor opens the curtain in the middle of the night, while I am in a deep sleep (*Image.5*). She has come to inform me that the diagnosis was pneumonia. At that moment, it was like a ray of hope, because the impression was that the condition was lung cancer. Later in the coming days, I would discover that my pneumonia was an

infection secondary to the cancerous growth in the lungs. But at that moment, when the doctor informed me about pneumonia, it was a positive message. The imagery represents ‘crepuscular rays’ coming from behind the doctor. These rays are magical to look at in the sky.

‘Lines’ bring meaning to the visuals.



Image.5

The same concept of hatching also features in the images below (*Image.6*, *Image.7*). In the top panel, hatching is used to create the lighting of the room, while in the bottom panel, it denotes the darkness of a deep sleep, with blobs of dream state. Playing with lines is not a new concept. It dates to the first printed books with illustrations.

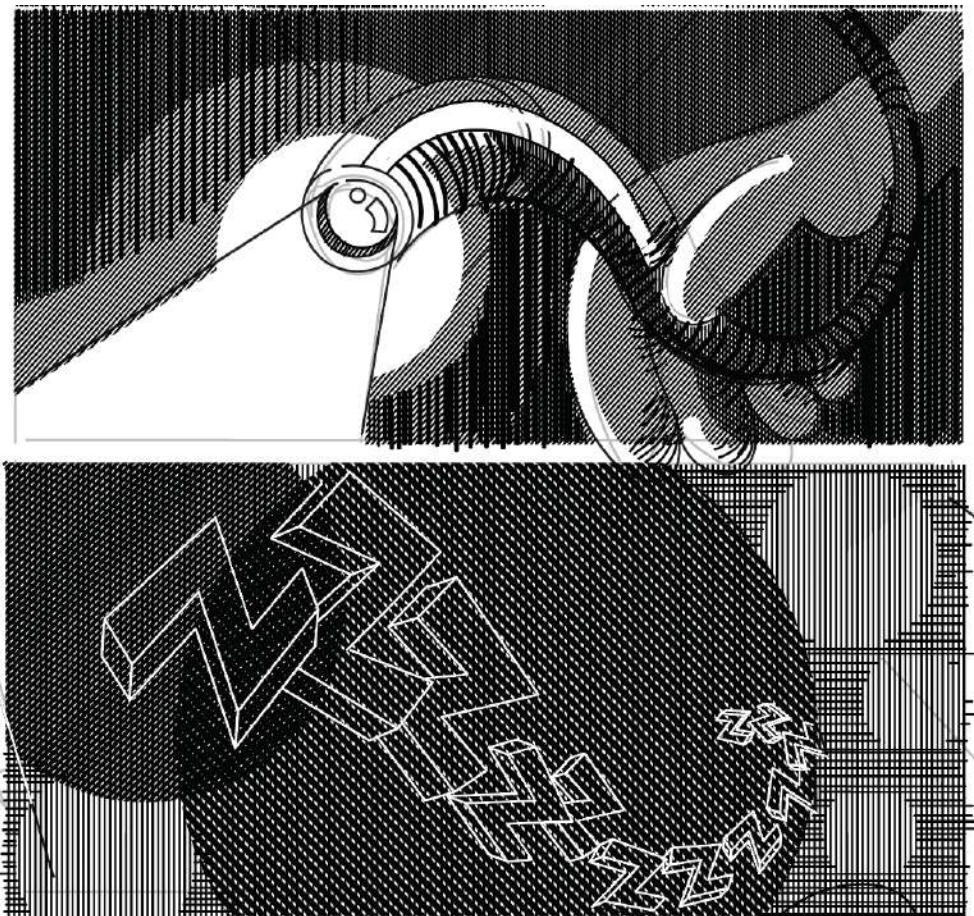


Image.6, Image.7

5. Speech bubbles

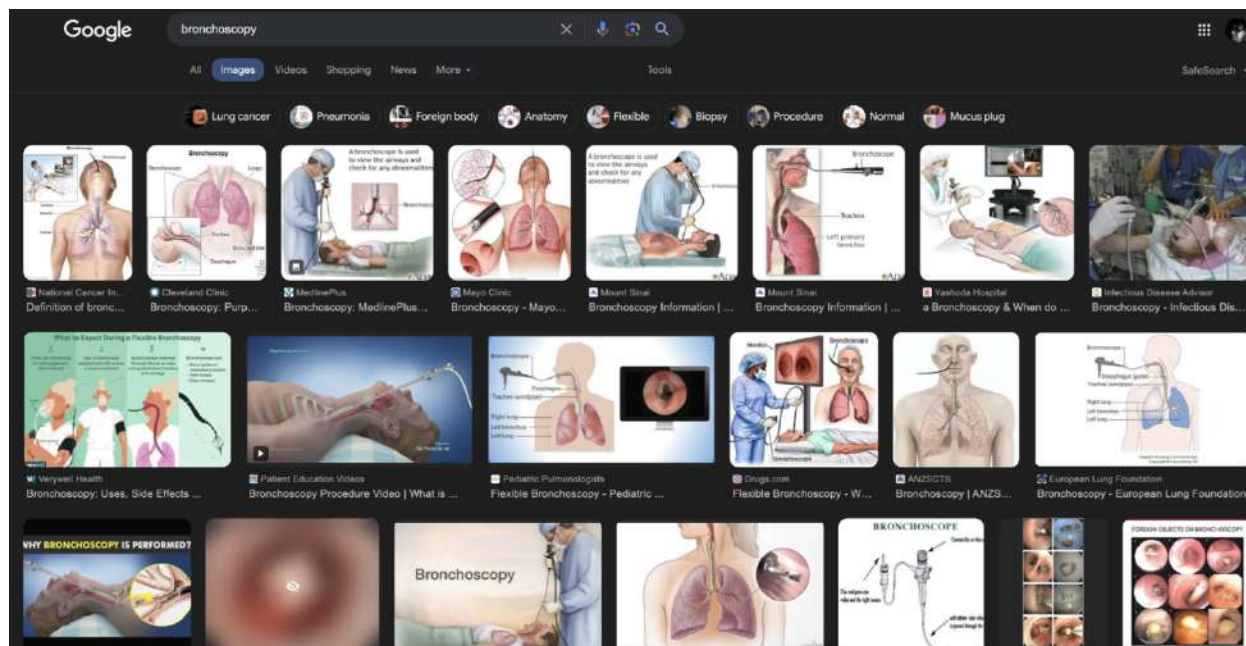


Image.8

Incorporating text with the images (*Image.8*) was the last step in ethno-graphy creation. The words that support the images are part of a symbiotic relationship between the two. The narrative structure incorporated in 1945 has multiple layers to it reflecting the nature of recollection, which does not happen on a linear path. Pockets of key memories first show up, which are then fleshed out by supporting memories, ultimately leading to a chain of recollection where multiple events are connected. The content spans a period wide enough to allow the narrative to jump back and forth, and speech bubbles and boxes with text in them play an important role in holding the story as a container. They also help the reader to navigate across the story. While the text is simple to understand, the images have more details for visual reading than the text, but this reading doesn't stand alone: the text ultimately provides context to the imagery.

What is the current state of existing imagery of health science?

As a patient, bronchoscopy was a new term I encountered when the doctor mentioned the procedure to be conducted for the collection of a biopsy. Reflexively, I accessed online information as a first step to understanding the procedure. Typing the keyword 'bronchoscopy' showed the images below (*Image.9*).



Source: <https://www.google.com/>, keyword: bronchoscopy

Image.9

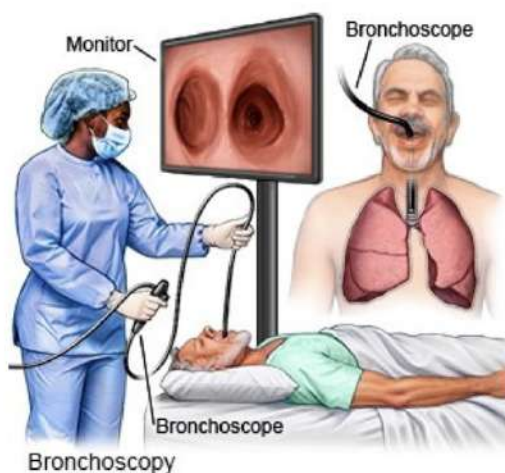
Medical illustrations are semi-realistic (*Image.9*), plastic appearing 3D models of human anatomy in science labs. These can be helpful for a healthy patient, but for one awaiting a critical procedure, these images look gory and frightening, lacking character and empathy.

Apart from the step-by-step procedure explained as words with illustrations, there

is no narrativized description of the patient experience in terms of the preparation for the procedure, the procedure, or the post-procedure. The information is often presented in simple terms using medical terminology.

Below are comparative images (*Image.10*) of the medical illustration and a frame from ethno-graphy, showing the procedure of the bronchoscopy. The rightmost image (ethno-graphy) captures the graphic nature of the procedure but is not harsh to the eye.

The medical team is having a conversation before the tube is inserted into the lung, reflecting the smooth talks medical professionals use to pacify the patient prior to the procedure.



Left of the frame Source: <https://www.drugs.com/cg/flexible-bronchoscopy.html>

Image.10

Techniques and tools to create

The drawings were created with Adobe Illustrator, which is a basic software that anyone can learn to use. Using this software has the advantage of producing an editable outcome in a vector format, which allows one to scale the drawings to any size-required, without compromising the quality of the linework. Creators can use the same drawings multiple times and make minor alterations to them. Five out of six images below (*Image.11*) are a single drawing of a face that was duplicated and altered, with new add-ons- based on the sequence. It reduces the production time, and through this process of creation, one learns exactly the right time and amount of effort to allot for creating each panel of drawing.



Image.11

Below are two lines, A and B. A is the original line and B is the scaled-up version of line A. The line remains sharp, this is because it is a vector (Image.12)

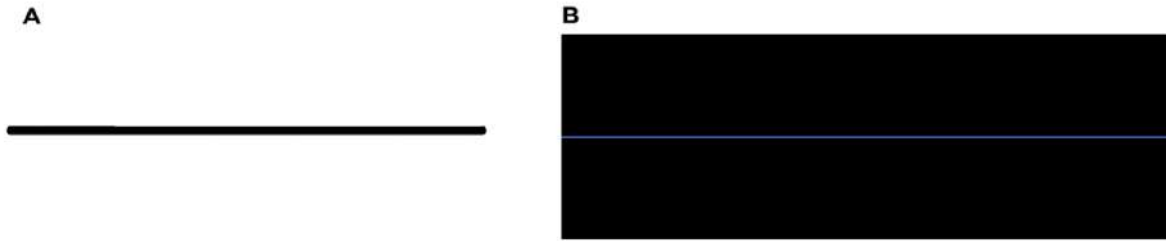


Image.12

The same line, when zoomed in as a bitmap, can pixelate. (*Image.13*)

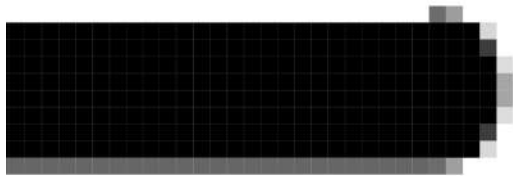


Image.13

Using Illustrator, it is also easy to do quick sketches to get the overall feel of the environment and people within the space. Creators can select and move each line drawn in the image. Below are the three stages (A, B, C) of refining the drawings. The red lines are a guide for perspective. (*Image.14, Image.15, Image.16*)

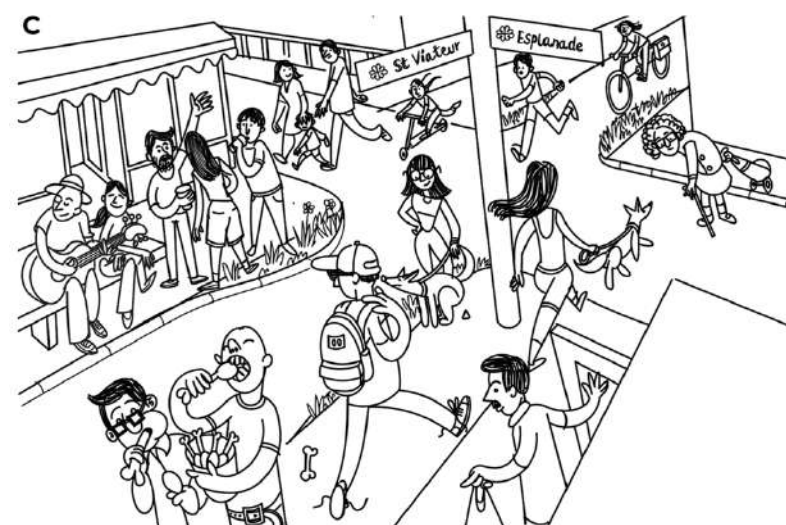
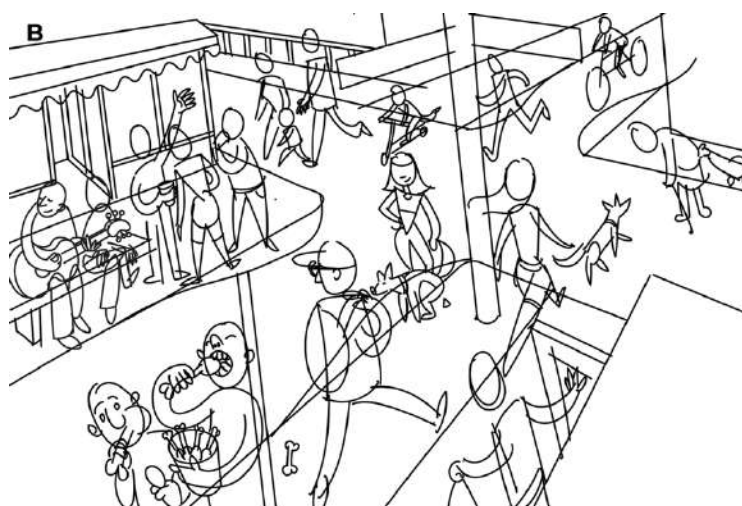
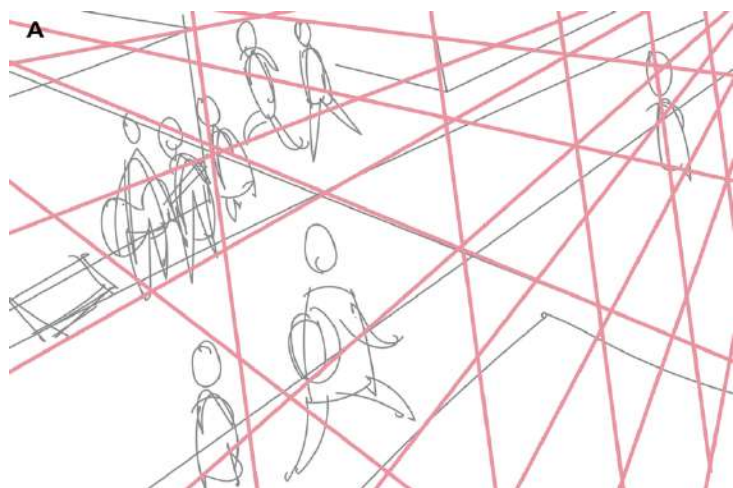


Image.14, Image.15, Image.16

Line thickness

Illustrator allows for instant changes in line thickness. The objects in the foreground have thicker lines, mid-ground objects have a middle-weight thickness, while elements/characters in the background of the compositions feature lighter lines. Even if they are black and white images, variations in line thickness can create a sense of depth.

Below is an example of the same image with different line thicknesses. (Image.17)



Image.17

Line thickness also helps guide the eyes in visual reading.

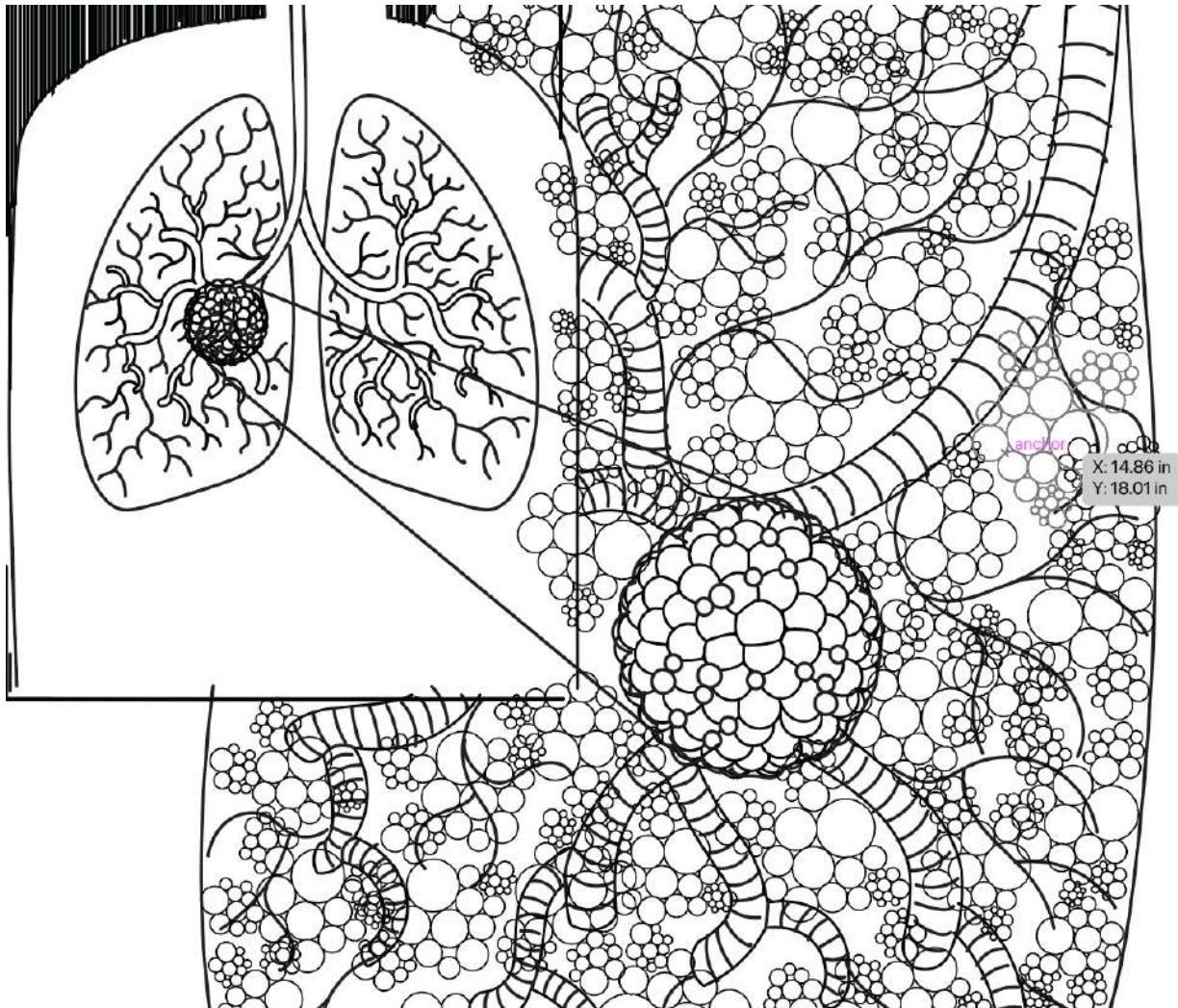


Image.18

Below (*Image.19*) is an example of showing various thicknesses of lines in the composition to create depth. Although not contrasting, it helps in the hierarchy of visual reading.



Image.19

Directly drawing with Illustrator is a quick and easy way to create sequential frames. The feedback loop can be fast, making the process interactive and facilitating quick iterations. It is also versatile for collaborations.

What were the thought processes while creating?

Working with sequences of images requires a specific thought process that encourages the perception of images in sequential sets rather than as individual elements, allowing the author to visualize the ideas navigating different pages as a big canvas. The images in the grid are different pages from the first chapter. The process of creating sequences of images comes from the concept of drawing storyboards for film. Storyboarding requires the ability to create a continuity of action where all frames are of the same size, and each image carries equal weight to the narrative buildup. Graphic novel creation in the context of ethno-graphy requires the ability to either manifest the continuity of the sequence or jump within the sequence.

While the story must be seen holistically, each section needs to be addressed individually, so that every composition has a unique character. The best way to achieve this is to do quick sketches across pages. Doing this in one sitting was not possible, so I broke the process into different segments, making an effort to maintain consistency while taking breaks. These breaks were used to reflect on what yet remained to be created, and ways to improve existing layouts and panels.



Image.20

The above image (*Image.20*) shows a sequence which begins with my token number being called out. I enter the cubicle, and the staff member of the hospital takes the details, then guides me to a nurse. There is a sequential order at play, and the gutter between the frames represents the passing of time between the two actions depicted.

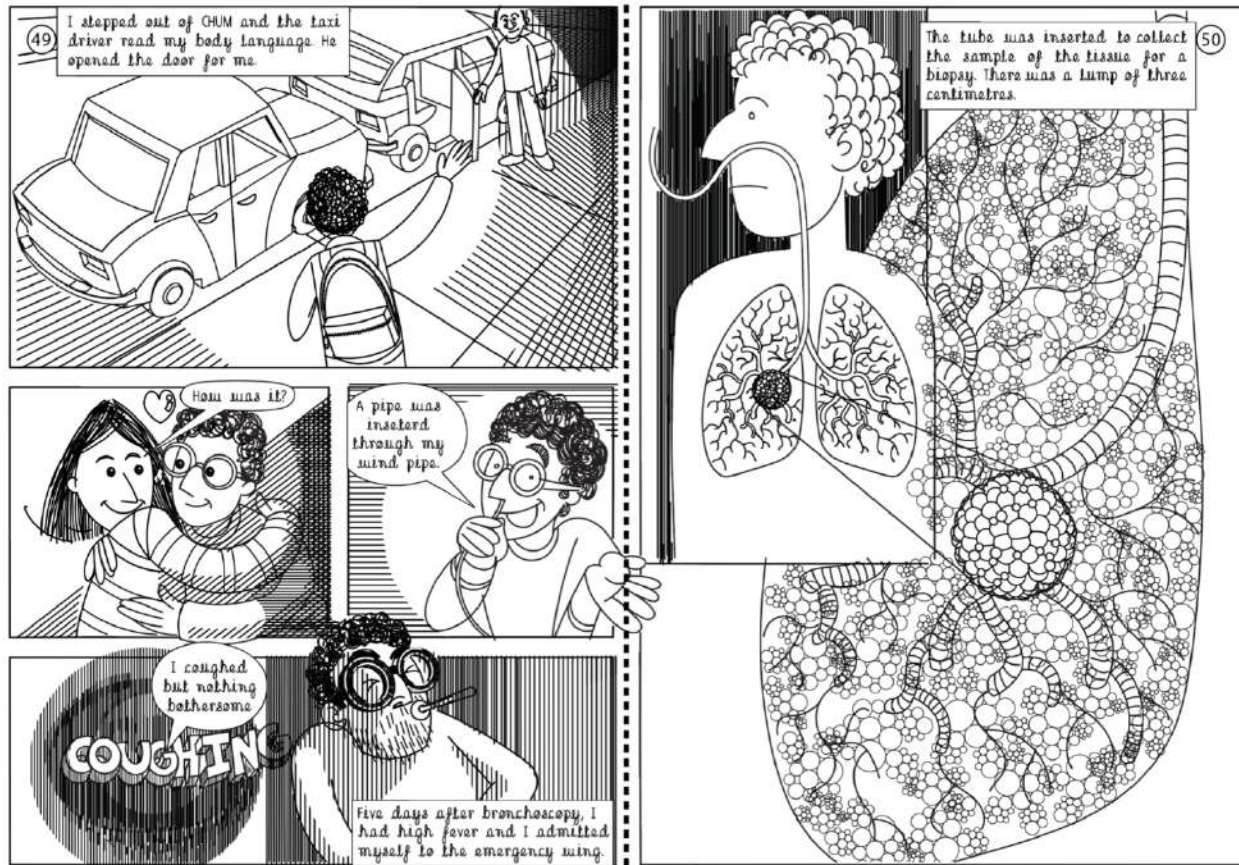
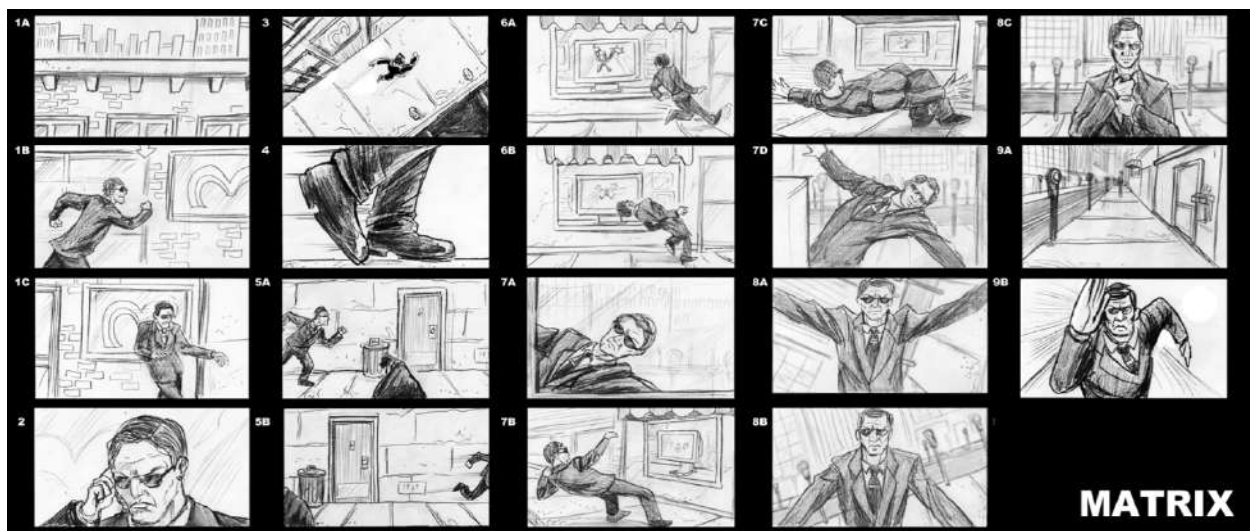


Image.21

The above image (*Image.21*) is a sequence that begins with my exit from the hospital. The next frame is about being greeted by my wife, and the third explains the procedure and the coughing it elicited while it was being conducted. In the fifth frame, the narrative jumps to five days after the procedure, leading to the sixth frame, which explains the procedure that followed. The frames serve as containers for events that have their own story. Enabling readers to use their imagination, the gutter between the frames acts like time travel. Readers may not understand (observe) the details of the graphic novels on the first read. When readers hold on to the book for a period and

revisit it to understand it better, each reading improves their comprehension of the narrative, because it offers further details to support the imagination.

There are several aspects that designers keep in mind while creating sequences. Unlike the storyboards, (*Image.22*) which have standard frames, sequential art has frames of different sizes. With the hierarchy of eye movements, the frame size plays a crucial role. The larger the frame, the greater its importance in the story and in the narrative structure. The smaller frames act as binding factors that form connective tissue between the two frames.



Source: <http://hardycases.com/contact/storyboards/matrix>

Image.22

Composition plays an important role, and not all frames have to be rectangular. The image below (*Image.23*) transforms a diagonal gutter into a hallway. This was done to communicate a state of mind that was confused, questioning, and uncertain.



Image.23

Diagonals can also be used within frames, as below (*Image.24*), where it helps show that I was in an unfamiliar hospital environment. Visually, diagonals impart the imagery with an off-balance look, relative to horizontal and vertical lines.



Image.24

Finally, diagonals also play a role in denoting speed and momentum, as shown below

(Image.25)



Image.25

What kind of tacit knowledge is required to do work of this nature?

To create sequential art is to have the ability to consistently achieve daily targets that are distributed across a period. Ethno-graphy creation generally spans a couple of months. One cannot achieve compelling results in a short period. It takes time for planning, effort to execute and is a reflective process. It becomes a task when it is rushed for the sake of completion.

Apart from the importance of consistency, it is necessary to possess drawing skills. This ability adds value to the creation of images and freedom to visual expression without the loss of consistency in terms of style. Additional requirements include the ability to tell stories and a firm grasp on key concepts of narrative structure. Knowledge of storyboarding in the style of film making pre-production helps in navigating how to transform an overall narrative into a visual context, as well as how to segment the narrative into visual blocks.

Advantages of working as an individual

Stories are human-centric, and the key strength of ethno-graphy lies in its ability to bring out sensorial experiences that contextualize and shape the feelings of individuals. Sometimes emotions lead to abstract spaces. This is true when experiences are

overwhelming. We dream in surrealistic spaces with overlapping imagery that we recollect during the day. Emotions can have a connection to these dreams. In chapter 2 of the graphic novel (not within the scope of MDes), the doctor enters the room just as I had returned from the second bronchoscopy procedure. While I was in the process of getting comfortable, or as comfortable as possible given the condition I was in, the face of the doctor fell. She said that the results of the biopsy had confirmed that my cancer had metastasized.

There was a fraction of a second pause that felt like ten minutes. Just like a dream that seems to last longer than it really does, in less than a second, my entire life flashed in front of me and got sucked into a spinning vortex. Imagine that this scenario was communicated by the participant to the researcher, who then further communicated it to the designers. The designers would synthesize the information the way they felt was right in order to represent what the participant felt. Yet in explaining the aforementioned moment in words, there is a loss of quality: language is insufficient to describe such experiences in totality. The advantage of creating autoethnography as ethno-graphy is that by taking up all the roles (designer, researcher, writer) in the research-creation, the designer has the ability to directly experience and remember that which it is their job to express, affording direct access to intricate details without others getting involved in the interpretation.

Challenges in teamwork

Researchers, scriptwriters and designers have varied backgrounds and different kinds of academic training. Each one of them has a different perspective and skillset. Researchers from different fields have their own ways of approaching their work. Scriptwriters may follow their own ways of writing, and the terms 'design' and "designers" relate to creativity involved in many types of work. The challenging part about ethno-graphy is to harmoniously unify-bring all these perspectives. The conceptual alignment necessary to achieve a collaborative aim is a challenge. Designers can have limitations in their abilities to visualize certain things, and often they prefer to work in styles that they are comfortable with. To create ethno-graphy, researchers should seek out designers based on their flexibility and their capability to create multiple frames.

What are the narrative structures used? What are the intentions behind the use of these structures?

Debate about finding the right way to explain a narrative abounds, and scholars have identified different approaches [66]. This research-creation endeavor concerns revisitation of a factual and personal story, and the narrative structure is based on my personal recollection of experiences. Recollection does not happen linearly. While experiencing the condition, I reflected upon what I was going through, and how, in a short period, everything in my life changed. The narrative structure was focused on facilitating the best expression of this experience, and the most accessible presentation of it for other patients. Because it is common for doctors to diagnose healthy individuals

who have been experiencing a good quality of life with ALK-positive, simply accepting the diagnosis can be the greatest barrier. What is the best way to communicate this to the community affected by this condition? How will they receive it? How can we convey this information to the community in a simple and approachable way that makes it easier for them to accept? How much effort does it take to read and process this content? Inner conflicts can cause cognitive overload. In “The Cambridge Companion To Narrative”, Marie-Laure Ryan breaks down semantics, formal and pragmatic dimensions for narratives that are used as a base for this research-creation.

There was a quest for finding the right kind of relatable story of lived experience of other patients with the diagnosed condition. In situations like these, seeking information is to save time, take precautions, motivate or get inspiration. It is for a level of guidance. At a subconscious level and sheer necessity, the stories of the community members did not have details in them. The autoethnography was based on the “**conditions of narratives in three semantics**” [66, 67] that filled the gap of the existing message that are found on the internet.

Spatial dimension: World-(s) inhabited by individuals should exist in the narrative.
Space can be revisited. Each revisit occurs at a different time.

The documentation is not centered around the specific medical condition but rather it is about various interactions amongst people and the infrastructure. During the diagnosis, there were several activities like visits to CHUM hospital, university health service,

attending seminars at the university, walking around the city of Montreal and meeting friends. These are the events and experiences surrounding the process of being diagnosed that did not hamper life. The ambience of the hospital when visited before and after being diagnosed looked different but that could be for various reasons. Regardless, there are sequences about talking long walks to Mont Royal as a discipline of maintaining the physical self which is an inspiration. Moments like these are shown in the narrative but in a subtle way.

The journey in 1945 has loops of visiting the same places and interacting with the people, with changing situations. This gives the reader the chain of events that is progressive about the diagnosis and the treatment, along with the context.

Temporal dimension: Changes are constant when time travels unidirectionally.

The available content on various platforms follows the narrative structure as synopsis of lived experiences. Change is constant but losing the details is loss of resolution of the narrative. It is not the elaboration of the story but to balance the chain of events, while retaining the resolution. In 1945, there are visual non- verbal cues in each frame for the observer but there is sufficient narrative as words, that can take the reader along the unidirectional path.

Mental dimension: Individuals should react emotionally to their surroundings. Here the mind can revisit space and time or recollect events.

The subject matter of the specific kind of health condition created a spontaneous flow of expression in detail. It was a gush of emotions, but the challenge was to have a balance of what was essential to the narrative.

Formal and pragmatic dimensions of narrative:

Sequences of events form a chain to come to a closure. Some events must be the key points (asserted facts) in the story world. The story should tell something make believe to audience.

Details in graphic novel

Graphic novels have a long shelf life. Readers revisit the stories over and over, because there are subtle details to be discovered each time they are read. In the image below (*Image.26*), one may not notice the duck and the ducklings in the lake on Mount Royal. These tiny bits of details come to life and add value to the story upon closer observation. Detail is a powerful quality of graphic novels.



Image.26

Another example below (Image.27) is the skateboard park at Mile-End where people are often shirtless. Skateboarders have a rugged appearance, and their features (here) include detailed, hairy armpits. These are reflections of observations, and intricate details capture the essence of the environment and the people.

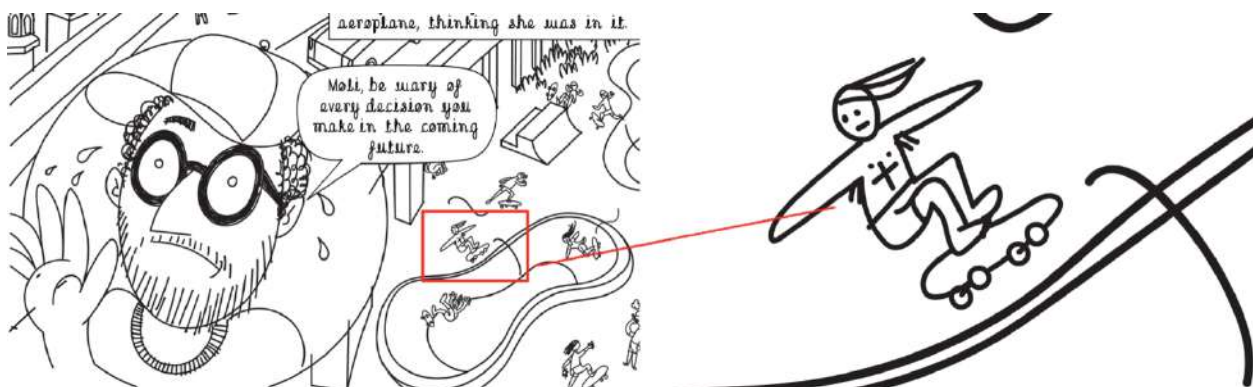


Image.27

Narrative design allows for the possibility for events to reappear or for the reader to jump to different parts of a story's timeline. It is easy to tell a story in chronological order, but narrative design presents events as various parts that fit together to form a

larger picture in which the overall narrative is easy to understand, potentially deviating from chronology. The author can provide the reader with a schematic overview that characterises the linear flow of the story (*Image.28*) to assist them in understanding chronologies.

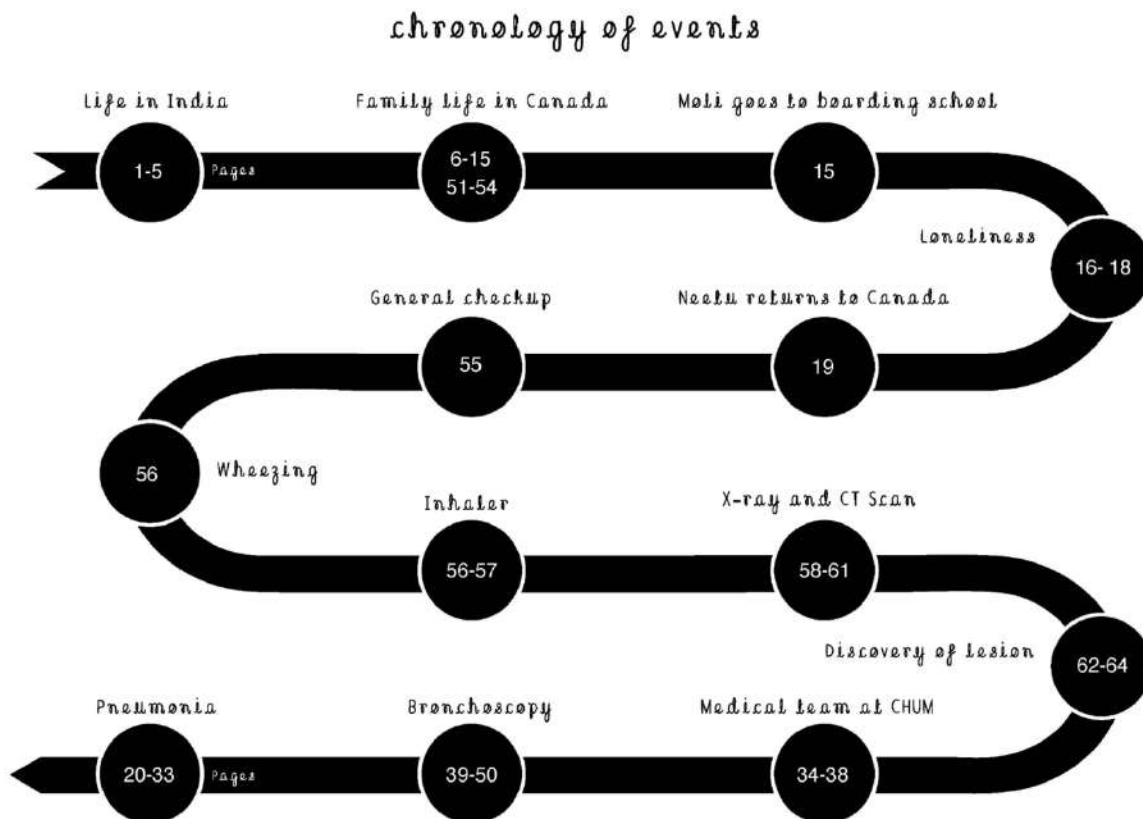


Image.28

The above image shows 'family life in Canada' distributed across two parts of the narrative. Cancer-focused content can be gloomy and negatively affect readers, thus

this content was interspersed with content not focused on cancer to introduce levity and highlight the beauty life has to offer. Page 50 discusses the bronchoscopy procedure, which marked the beginning of the low point of my experience, because it involved conducting a biopsy, and pages 51-54 show beautiful moments that break these low points.

This approach can be used to recreate almost any lived experience: it enables storytelling focused on detail and the revisitation of dark experiences with a sense of lightness. The image below (*Image.29*) on the right of the frame is a selfie (for documentation) and to the left is the same situation where I am curled up in pain.

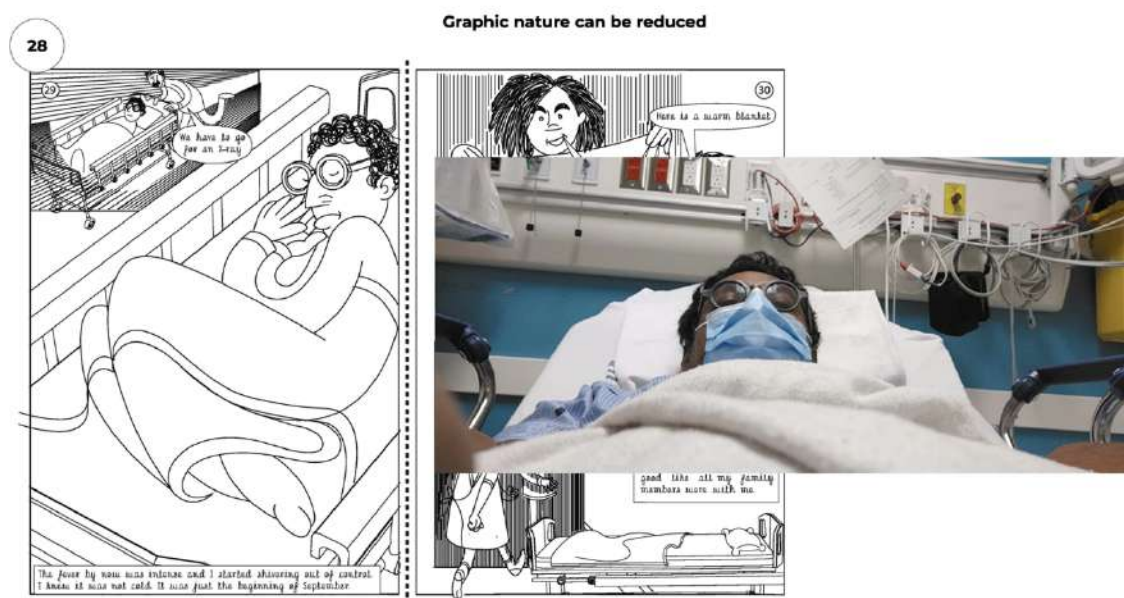


Image.29

Observing my surroundings was a continuous process and I kept taking photos as documentation. Below is room 1945 (Image.30).



Image.30

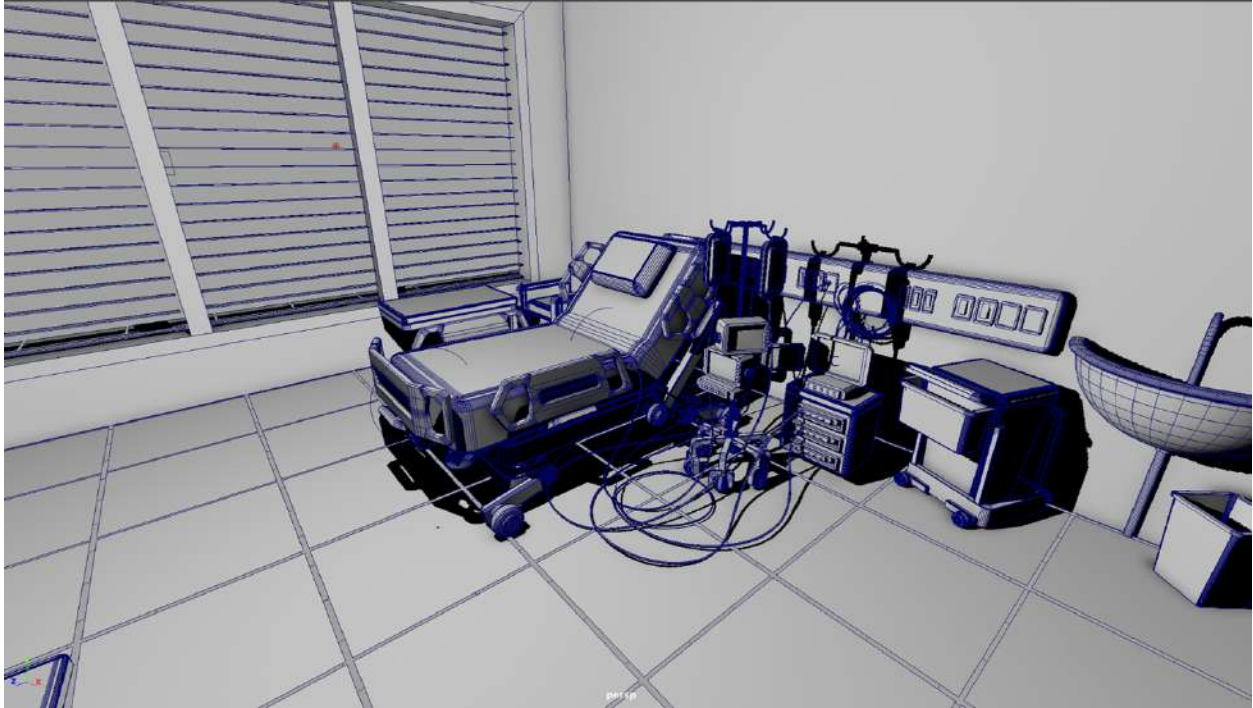


Image.31- Recreation of the same room as a virtual set

Below I feature a sketch of the process of making a mask which would prevent my head from moving during radiotherapy (*Image.32*). The radiotherapy procedure felt nothing short of an alien abduction incident, complete with experimentation and probing robotic arms destroying cancer cells in specific parts of my brain. My head was locked in place, and the slightest move made these arms recalibrate their position to ensure they were on target. It felt like these machines had minds of their own. Timely documentation of experiences like these helped me later incorporate them into the narrative structure.

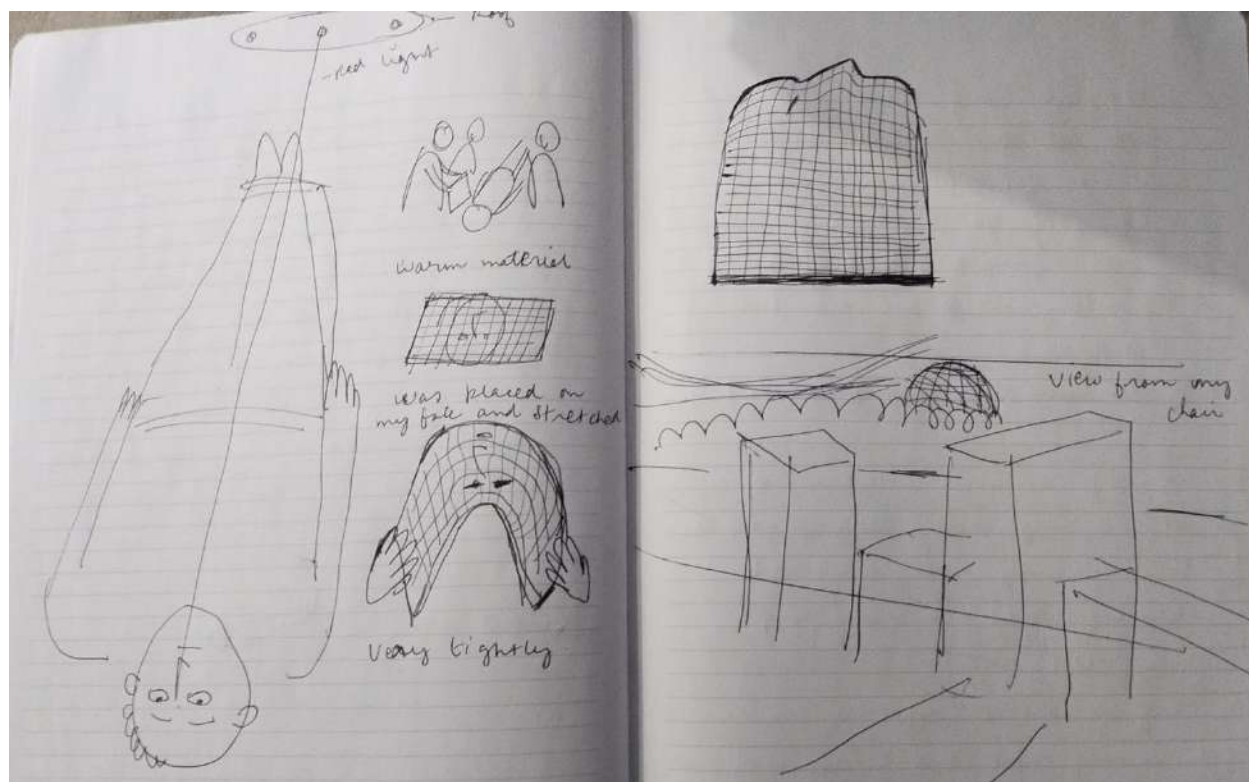


Image.32

The beginning of the story

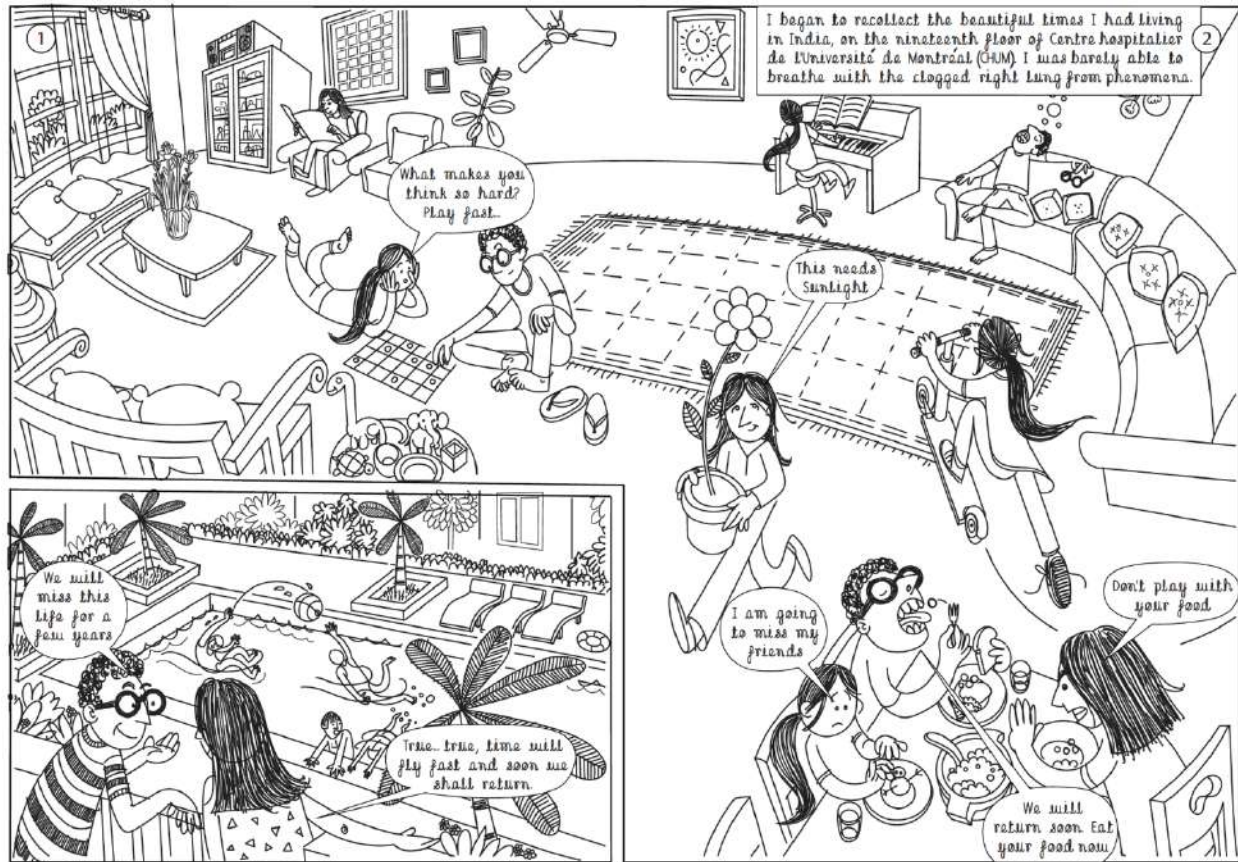


Image.33

The story opens with a bird's-eye view of the living room (*Image.33*) where most of my family's domestic activity used to take place. The composition deploys a convex shape because the distortion allowed me to capture much more of the space. The same composition with conventional perspective drawing would make farther things smaller in the composition. The distortion gives equal importance to the activities within space.

This is the concept of grand opening, borrowed from filmmaking, commonly called the establishing shot. It builds the context of the scene with the characters [68]. It welcomes the reader to become a part of the activities. In this living room composition, the space captures various moments in time, showing a Sunday morning newspaper reading, an afternoon board game, an evening piano session, a quick nap, moving pots before the Sun sets, and conversations at the dinner table. The span of time represented here could be sequences of events on the same day, or snippets of activities captured from different days, or even spread across weeks and months. It is open to the reader's interpretation. The idea here is to show a recollection of a life filled with action and energy.

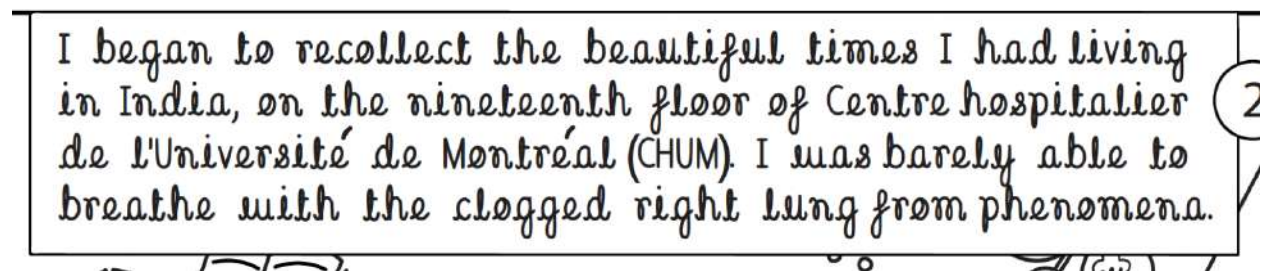


Image.34

The protagonist, when he is lying on the hospital bed recollecting these events, is nearly unable to breathe because of pneumonia (*Image.34*). While the visuals depict the beauty of life, the text describes the difficult condition which led me as the protagonist to an active appreciation of it. A key strength of graphic novels is that words complement visuals, and vice versa. There is a contrast between the physical state described

through text (in a hospital with a frightening health concern) and the mental state represented visually (recollecting the beauty of life). By introducing this conflict, it captures the reader's interest as they seek to find connections. The reader is invited to piece together the information to uncover the person's identity and the cause of their hospitalization.



Image.35

Within this composition or sequence of events, the main characters' nature becomes apparent. It shows a twelve-year-old outsmarting her father in a board game, as the latter is taking time to make the next move. With no speech bubble (*Image.35*), it would have been harder to communicate this dynamic.



Image.37

At dinner time (Image.37), the young girl makes a snowman with her food. She says that she is going to miss her friends. The mother asks her not to play with her food, while the father is tossing a pea into his mouth and speaking at the same time. It is unclear why the girl is upset about missing her friends. It's clear that the father is coaxing her.



Image.38

The details of the living room are drawn from photographic capture of the corresponding real space (*Image.38*). Despite the wide-angle lens, it was not possible to capture the entire space in a single photograph. The foreground elements are large while the background elements diminish. In compositions like these, there is an order of visual reading, wherein the elements closer to the frame take precedence over the background elements.

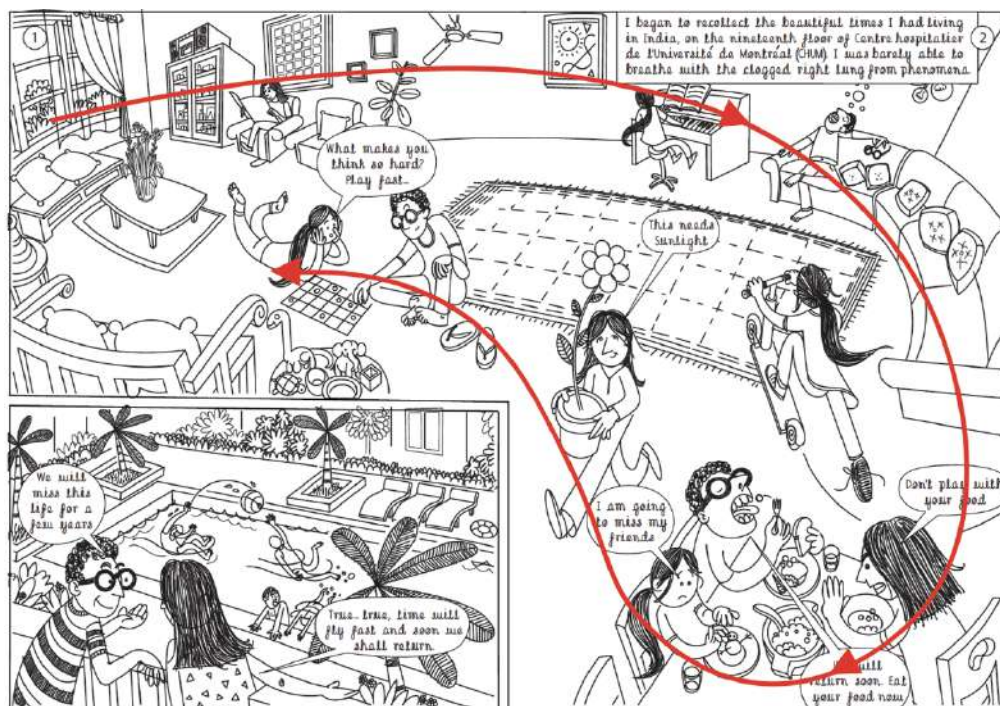


Image.39

The image above (*Image.39*) shows how the visual reading flow begins from the left of the frame near the window. It then moves to the person reading the newspaper, the piano being played, snoring on the sofa, and eating a meal at the dining table. The eyes are ultimately directed to the centre of the frame, where characters are taking

actions like riding a scooter, relocating a flowerpot, and playing board games. The composition encourages the eyes to move in an arc that gives a sense of the entirety of the living room, including the activities it housed.

In this frame, foreground elements (characters and props) can be larger than the background, but the design of the layout plays a role in the visual reading. Various artists have used these concepts. For example, Edvard Munch depicts the release of tension within the individual in “The Scream” (*Image.40*) by using distorted surroundings that create a wavy effect. Multiple eye movements within the frame cause the feeling of tension. One of the eye movements starts from the right of the frame, goes to the background, passes the two secondary characters and heads towards the foreground main character.



Image.40

The knowledge and ability to come up with various kinds of composition develops over time, through trial and error. Practice is required to create the ideal visual composition for telling stories in an effective way. Spontaneity is required to create a series of drawings in a sequence that comes from tacit knowledge. Rather than focusing on perfecting any individual frame, this approach demands a higher level and broad perspective, in which various images work hand in hand to convey an overall feeling and narrative.

2.5 The feedback loop

To test the effectiveness of the research- creation, Chapter 1 was shared with various teams which had CHUM doctors, case management service, ALKpositive.org and the Patient Support Program. These were the responses received.

- 1) The doctors felt the visual representation of the patient's feedback was a new kind of expression and came as a surprise. They also saw the potential of a visual form of representation of the sequence of events and the importance of telling an elaborate story.
- 2) They liked the nonlinearity of flashbacks, building to the chronology of events.
- 3) The content was accessible to read, which is one of the challenges for patients.
- 4) The doctors were eager to discover pockets of stories within stories.
- 5) The drawings give direct access to the lived experience in a way that telling with text would not be able to capture as purely or richly.
- 6) Chapter 1 shows many different players/parts in the healthcare system
- 7) In most cases, the patients can feel their experiences but spend less time expressing themselves. In this case, the experience depicted visually can make a difference.
- 8) The content can be used in patient support groups and handed out at the hospitals as an educational tool for medical teams and for help people open up and talk about their experiences.

The effectiveness of ethno-graphy as a medium was anticipated. The literature review of ethno-graphy has a similar nature of feedback the researchers received in testing out content in this format. The level of engagement of the pilot project of ethno-graphy showed the same results. It is an effective way of telling real stories with the intent of social awareness and transformation. It is motivating for the creator and the audience. It acts as a medium of giving the pleasure of making the research material accessible and to see the audience engage with the content. Making research not confined to researchers.

Other observations

As a designer by profession and a patient diagnosed with ALK-positive, I experienced the hospital environment for the first time and have to be on a regular visit for a year. From these experiences, it is evident that regardless of the efficiency, the entire system works, there are opportunities for designers to find solutions. The functioning of the hospital system has built over the period of learning. There is a lot of human interaction and coordination required between the employees of the hospital and the patients. Some of these are repeated patterns of communication that could be optimized through digital interfaces. The detailed stories of patients can enable to develop better health care in the hospital.

Concordia University Health Service, CHUM and Health Department of Quebec

The team at CHUM acted in quick response when the fax message was sent to the health department of Quebec- from the Health Service of Concordia University. It is the timely response that saved my life because the type of cancer never showed any signs, until the very last minute. In my case it was wheezing that could have been brushed aside as seasonal allergy. When inhalers did not respond, immediate actions were taken for further investigation. It is to acknowledge that with this rapid action, it would have been impossible to have been able to share the experience.

Sharing with ALK-positive community and discussions

The objective is to share the graphic novel with the community of ALK-positive groups which are active in spreading awareness of the condition. ALKpositive.org is one such group that is run by patients. They invite guest speakers, usually doctors, who discuss hard facts. After sharing the Chapter 1 with ALK-positive.org, they want me to speak about the story of creating the ethno-graphy.

Based on the research-creation, a step-by-step process will be shared with the audience, so that the community understands this nature of documentation. They can learn to tell stories in this format or collaborate with visual narrators. Various parts of the world can have different medical and other supporting systems that work for patient support (which I am unaware of as a patient). Sharing in this format (and probably building a repository) can help people understand the different nature of support

systems that can help the patients and medical team to adapt to certain processes to optimize the condition, care and control of ALK-positive.

3. Conclusion to the research-creation

There are ample stories online about people who have experienced ALK-positive, but by and large these stories adhere to narrative structures that proceed as follows: “I was leading a healthy life, I started experiencing breathing problems, I discovered I had cancer, I received treatment for the condition and I have returned to normalcy.” Another issue with current narratives is they are frequently sparse when it comes to specific details related to the condition. To address this shortcoming, I developed an autoethnographic account of having ALK-positive that relays vivid and accurate experiential detail using an ethnographic format.

As a patient seeking information, even accurate, authentic content is flawed in certain regards: in general, it can be delineated into two types. The first type is a style of educational material provided by medical professionals who specifically provide information about the condition. The second type takes the form of testimonials where patients share their lived experiences through stories. These two types exhibit variations in their messages. The former is about understanding the condition, while the latter is about going through the journey of dealing with the disease.

The websites categorize content into “information” and “blogs”. Information can include disease-specific details, while blogs feature movies and written content that depict lived experiences. The documentation for these categories is problematic. The blogs only provide a brief glimpse of the journeys of being a patient. This merely offers an overview of the key areas of experience. The storytelling patterns are mostly similar with few variations. There is a lack of ‘thick description’. The quality of the narratives is poor: they are not engaging, motivating, or inspiring. The structure of editing movies or reading materials is similar. These stories should rejuvenate the patients, give them confidence and information through the lens of detailed lived experience, but this important potential remains uncaptured through the currently existing accessible materials.

There is a need for quality information, as it is evident that a large community accesses the internet for answers, but they enter a quagmire. What does it look like to create and provide the public with authentic, detailed, informative, engaging and accessible content- relevant to the condition, care and control of lung cancer?

Taking this experience as a starting point, I began a research-creation process geared towards the formation of visual autoethnography. Until my diagnosis, I had been using a combination of design ethnography, semi-structured interviews, and participatory design to pursue my research-creation intentions. After my diagnosis, I re-oriented my use of these methods to undertake self-reflection, and to document my experiences of being diagnosed and getting treated for ALK-positive. Here, my journey of diagnosis to care is documented as a 'thick description'. The research-creation counterpart takes the form of ethno-graphy, using images and words to document the different systems that supported me as a patient in Quebec.

One of the challenges in the age of information is misinformation and disinformation. The quality of content of this nature is brief and has no clarity. Healthcare content is flooded with short stories to capture the attention of the audience for various reasons. In this research-creation, the narrative is broken down to every detail that gives a clear chain of events of the individual leading a daily life. It has a 'thick description' with authenticity and multiple stories put together like these can create an impact on understanding the harsh realities of experiencing conditions like ALK-positive in an engaging way.

Based on the literature review, it is evident that the content has to be accessible to people with reading ability between the range of secondary to early high school

levels. The words and visuals make the content easy to read. Visuals play a large part in narrating the story by reducing the cognitive overload.

If the content is in a printed format, it has a long shelf life, like an old magazine can be read multiple times. The plans are to get these printed and place them in the hospital. It serves as an inspiration to the patients. It also shows the detailed journey of being a patient and the experiences the patients can anticipate. By looking at this creation, it will enable the patients to express themselves. This can also help the family members surrounding the patient to get a sense of the entire journey. Stories like these make people feel that they are not alone.

The journey of the patient is interconnected with the co-ordination of various groups who directly or indirectly interact with each other. A narrative like this will bring people together and they will learn about the various roles played in health care. One example is- the case management service member will learn the way pharmaceutical optimize their delivery of the pills. Or the oncologist will know more about the taxi service in the hospital.

The doctors and the healthcare teams serve the patients relentlessly. This work is a gesture of their effort in serving the patients. Their service is visually depicted and documented as a patient's record of the doctors- which is vice-versa of the doctor's record of the patient.

Finally, research-creation emerges from an amalgamation of methods- borrowing concepts from ethnography, participatory design, and semi-structured interviews. It is a piece of research work that is designed to communicate the researched content. The intent was to make the research material accessible to the general mass. After sharing the first chapter with various people in the system of health care, it is evident that ethnography has potential in it.

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Appendix

Montage of the thought process

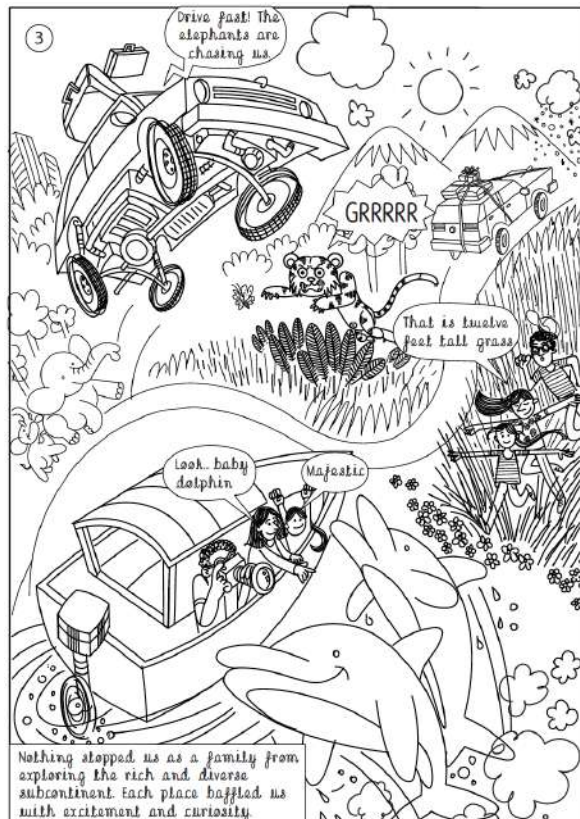
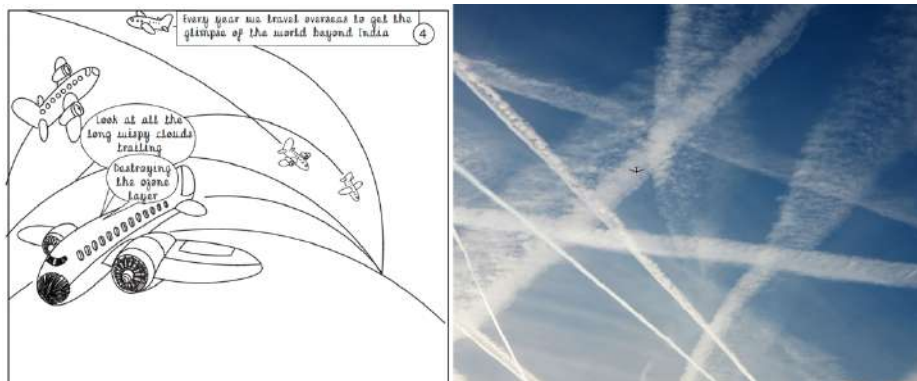


Image.41

The living room (*Image.33*) shows multiple activities at different times, within the same space. The above image (*Image.41*) is a depiction of juxtaposed imagery possessing various spatial as well as temporal dimensions. It visually describes the grandness of the topology on the sub-continent of India, reader has the option of perceiving it as a single journey or interpret it as a collection of experiences at different times. The composition does not have boundaries in terms of frames and the eyes flow across a page filled with freedom and wildness, anticipating tiger pouncing and

elephants chasing the car and conjuring the joy of travelling. This is to give a sense of life back in India.



Source: <https://www.scientificamerican.com/article/why-do-jets-leave-a-white/>

Image.42

There are minor stories nested within the bigger story. A small segment talks about 'chemtrails', a conspiracy theory regarding the supposedly deliberate release of chemicals from airplanes (*Image.42*). There is no evidence of it, but it is a detail that flyers observe when they are high above in the sky. People often notice streaks that cut through the fluffy clouds. -Travel does not come without a carbon footprint.

The image below (*Image.43*) shows the family in a discussion about a famous painting by Picasso: - 'Guernica'. The conversation is about cubism or surrealism. It is a minor story that has no connection with the major story. These are the build-ups in the narrative.



Image.43

Source: <https://www.britannica.com/biography/Pablo-Picasso/The-1930s>

The double spread (*Image.44*) has various spatial, temporal and mental dimensions combined. A strength of the graphic novel format can be found in its ability to hold pockets of information within frames that are standalone stories. These minor stories contribute to building up the larger picture. Within this spread, the reader embarks on a journey across the subcontinent, traverses half the globe through undescribed territory, and finally arrives at a particular museum where 'Guernica' is displayed.

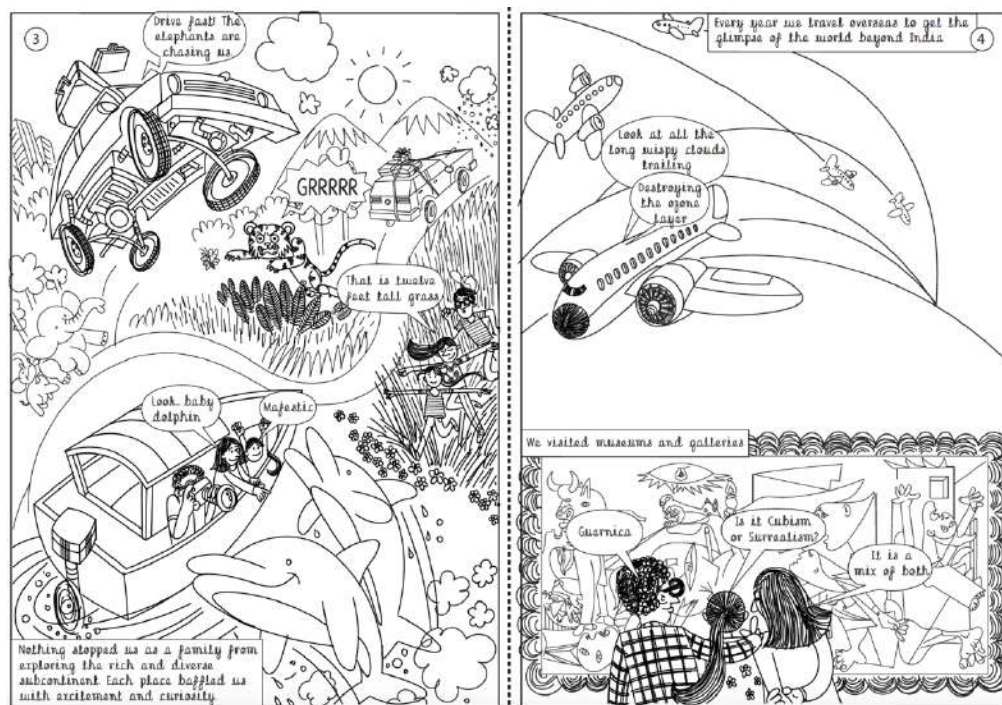


Image.44

Through the addition of subtle details, the depiction of the specific location attains authenticity. Combining people with the way they use their surroundings allows us to capture the atmosphere of the place. The first impression I had of the corner of St Viateur and Esplanade Ave was that it was a junction with a lot of energy and activity. My impression of this energy is what made me choose it as a place to live.

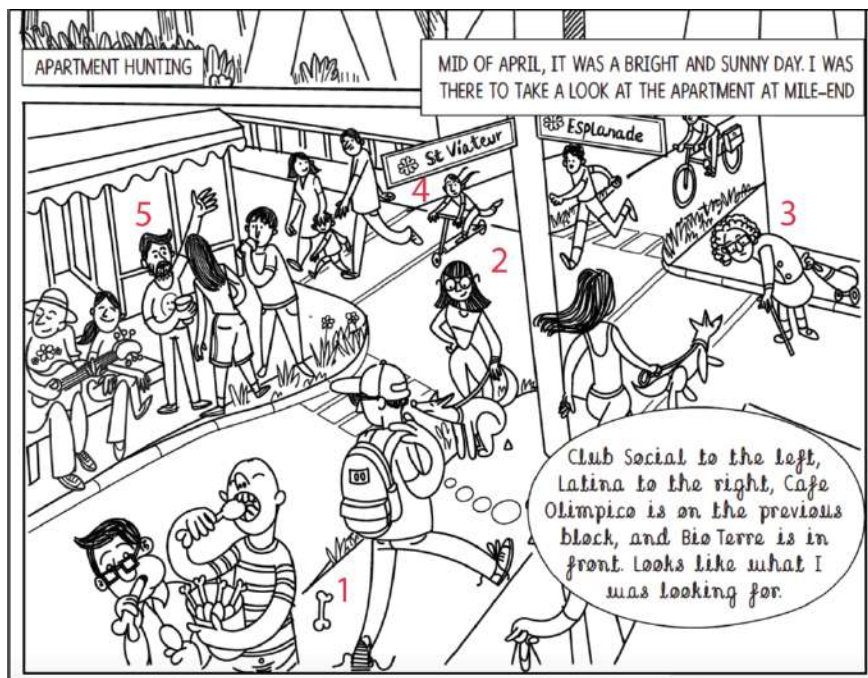


Image.45

Capturing the city: Corner of St Viateur and Esplanade Ave (Image.45, Image.46):

- 1) It is common to find bones in front of the Portuguese chicken shop. People grab a quick meal, have food on the benches and end up tossing the bones. The chicken leg bones are characteristics of the opposite side of the Club Social.
- 2) The expression on the face of the dog owner shows a sigh of relief when the dog is squatting. It is every dog owner's sigh of relief, as dogs take their time, and the owners are forced to wait patiently.
- 3) It is common to spot this elderly woman crossing the street as she collects used soda cans. She is a fixture of Mile-End and has a tiny dog. Living in this part of the city, one gets to know people in the community.

4) A child from the Hasidic community freely rides his scooter with confidence. This is a common occurrence; tiny kids loitering around freely as individuals and as groups. The confidence they show from moving around clearly shows that they are under the supervision of the community members.

5) Regulars at Club Social engage in expressive conversation. This is a corner where one finds the same loyal faces, and their presence is almost like a religion. It is also common to see young couples with kids walking around this area. The idea is to show the level of comfort that this community bestows to one another through their body language and actions.



Image.46 Image for Club Social.

Sources:

[https://www.tripadvisor.ca/Restaurant_Review-g155032-d7289264-Reviews-](https://www.tripadvisor.ca/Restaurant_Review-g155032-d7289264-Reviews-Club_Social-Montreal_Quebec.html)

[Club Social-Montreal Quebec.html](https://www.tripadvisor.ca/Restaurant_Review-g155032-d7289264-Reviews-Club_Social-Montreal_Quebec.html)

<https://www.schlouk-map.com/en/places/cafe-club-social>

St Viateur bagel shop (Image.47, Image.48)



Image.47

This grand frame shows parts of St Viateur Street, capturing the beauty and the energy of my neighborhood, and the excitement and happiness of its community. Everyone in my family found the St Viateur bagel shop fascinating, as it drew a constant

throng of people flocking to get hot bagels. The seamless integration of tourists, visitors and locals always surprised us. Expressing detail of this type in words is not easy, but visuals can effectively communicate a great deal of information and feeling economically. The frame design allows one to feel the essence of the surroundings at a glance. The frame also has subtle details that readers can associate with their own personal experiences of this surrounding.

The layout features a bird's eye view with a distorted lens, with a vanishing point to the top right of the frame.

Here is the breakdown of the captured details:

- 1) Couple from the Hasidic community pushing double strollers.
- 2) Two dog owners interacting with each other's dogs. The small dog lies on its back. A belly rub is being given to the dog by its owner. The big dog is crouching to play with the small dog.
- 3) People sitting on the benches to eat their bagels that they could not resist coming to St Viateur for.

- 4) The line that is present at the bagel shop during the weekends, revealing the excitement felt by people entering the shop and waiting for their turn to place an order.
- 5) A conversation between two strangers spurred by one of their dogs.
- 6) A family who are excited to see their father/ husband walking out of the shop with a bag full of bagels.
- 7) A woman looks across the road and smiles at our dog, Vanilla.
- 8) A Hasidic man giving a side-eye.
- 9) An older couple, with a woman who is unhappy with her husband's uncontrolled gobbling of the bagels.
- 10) Garbage bags near the dumpster for the Monday morning pickups.
- 11) Workers from the restaurants taking a minor break and smoking cigarettes.
- 12) My family absorbing the vibrance of the surroundings.

Below are actual images of the bagel shop. The advantage of creating a drawing is that interesting details can add value to the surroundings, and authenticity can be

preserved. These interesting activities are curated from various observations made over the period of passing by the bagel shop.



Image.48 – Images of St Viateur bagel shop

Sources:

<https://www.stviateurbagel.com/en/our-story>

<https://vancouver.citynews.ca/2017/05/21/montreals-famous-st-viateur-bagel-shop-still-rolling-60-years-later/>

Sketching from photographic memories



Image.49

In the age of the digital camera and the smart phone, nearly everyone possesses a massive database of photographs, accrued over time through the simple use of their handheld devices. Developing photographic memory takes this phenomenon to the next level, and proves handy in developing the practice of visual thinking. The entire graphic novel is based on this ability of recollecting the experiences that were stored as images in the mind. One can always go back to reference photographs, but it is even easier to retrieve and reference-images stored in the mind to create sequences spontaneously.

Without seeing the inserted photographs (*Image.49*), I created the drawings in *Image.49* from memory. There are striking similarities between the drawings and the photographs taken. Although they do not look the same, they are similar. An advantage of composing a drawing can include the deliberate conjunction of compelling images that attract immediate interest. The drawing depicts the lake on top of Mount Royal, iconic to the region, in the top right corner of the frame, and also includes the vision of downtown on top of the frame. It is not possible to capture the lake, downtown, protagonist (and pup) in one photograph, as they are not close enough to fit in a single frame unless taken via drone, which will only give a top shot with holistic details.

Before the diagnosis, I used to take photographs as a recording of our daily walks to Mount Royal, and they came in handy in reflecting upon and building the context for the story. While photographic memory can facilitate reflection, photo documentation proves to be useful as well.



Image.50

For example, see above my examples from my documentation of hundreds of random writings (*Image.50*), cutouts, and stickers on the walls around Mile-End during early morning walks with our dog. The motivation to capture these expressions came from my curiosity about why people would be so random with words. What motivated the creators to express themselves in this manner? These minor acts of documenting daily life and reflecting on it were used to support the narrative in the graphic novel by adding details that show that life was beautiful and enjoyable. The top left drawing is from the graphic novel, showing the documentation process of these scribblings. The photographs are examples of human expressions, or from another perspective, perhaps simple vandalization. These expressions may go unseen to the public as they pass by, unless those passers-by are paying attention, but nonetheless the scribblings have

increased exponentially over time, with layers and layers of messages in the past year.

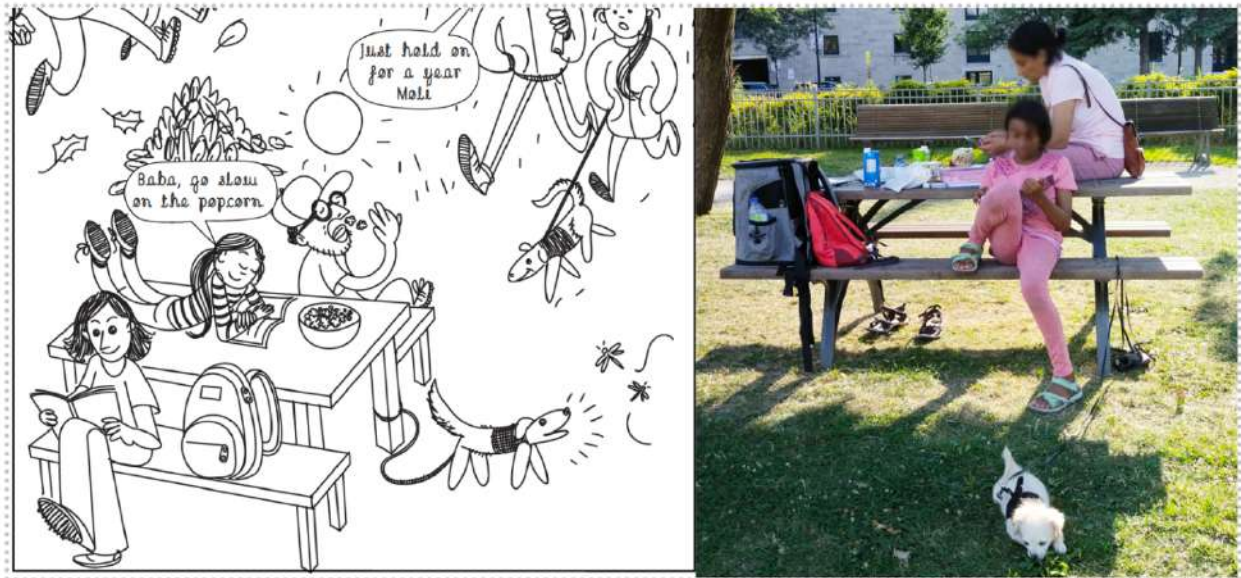


Image.51

The drawing on the left of the frame was created from memory. Upon revisiting the photographic documentation, there are differences in the composition (*Image.51-55*). The drawing captures the essence of the scene and reduces unwanted details in the photograph. The mind records the memory of a particular situation with holistic detail, rather than specific details. Drawing from memory has its advantages, as the mind and memory organically synthesize the essence of the situation. This supports the recreation of a particular experience, which supports and gives life to the entire story. It is not about detailing a frame but scaffolding a narrative.

Even though there is photographic reference, and each subject is busy doing their thing within the frame, the mannerisms of the family are composed to convey a sense of humour. Although this is ethno-graphy and it is based on facts, the aim here is to mediate the story in a way that makes it easy to engage with. Liberties are taken with space and recollection in order to add value, in this case in the form of levity, for communicating authentic information. This is a buildup to a narrative that enters the darker aspects of human life.



Diwali celebration, festival of lights, *Image.52*



Christmas time, *Image.53*



Autumn/ Fall season, *Image.54*



The winter of 2022, *Image.55*

Each of the above images is a documentation of a set of events distributed across temporal dimensions. The parameters of those temporal dimensions could be a few days, weeks, months or even years. Below (*Image 56*), I have combined these into a single frame, while preserving the time gap between each event. The image represents the cycle of one year, communicating the passage of time by invoking seasonal changes. Simple formulas also work well, but it depends on the presentation. In the image below, the shape of the year is circular, and so is the path the eye follows, similarly to the way the Earth orbits the Sun.



Image.56

Analysis of websites

Analysis of <https://cancerquebec.ca/>. This an example of the way each website was observed from the user experience to the content available

Cancer classification:

Reflections: Two sentences explain the type and grading of the cancer through the examination of samples of cancerous tumors collected by biopsy.

Cancer grade:

Reflections: The language is broken, and the sentences do not make any sense as there is jargon used. “The resemblance of cancer cells to its original tissue is more or less faithful”.

In this sentence what can the “original tissue” mean and “more or less faithful”? What does the word “less faithful” mean? It is hard to break down a sentence of this nature and it takes a lot of effort to interpret it.

Information like- higher-grade tumors develop faster, the lower grade is slower with more local evolution. Grades are qualified from 1 to 3, some are from 1 to 4 or 1 to 5 and this corresponds to the degree of cellular differentiation.

What is a grade? Why is it between the range of 1 to 5? What does the range indicate?

Histological classification

A table explains various kinds of cancers, their tumor tissue origins, frequency (share of each kind of cancer in percentage) and location (where it affects).

Reflections: the table gives a schematic view of various kinds of cancer and a layout to get the idea at a glance.

Cancer prevention

The listed topics were stopping smoking, protecting skin, maintaining weight by lowering it, being active, avoiding consumption of red meat, eating vegetables, fruits and legumes, reducing alcohol, reducing products with salt content, no use of supplements.

Reflection: This section was an easy read that touched upon every area but did not explain in depth. Information has to be justified.

Definition of cancer:

This section gives a basic understanding of cancer which is generic.

Cancer facts and statistics

Reflection: Updated statistics and information on the number of people diagnosed with various cancers in Quebec. Every eight minutes, someone learns that they have cancer, which is 180 new patients every day or 64,800 in one year.

Cancer screening

Reflection: This section is for the early detection of cancer, a brief touchpoint on ongoing innovation and the advantages and disadvantages. It has nothing to do with patients already diagnosed with cancer. The reason for its presence has no real benefit as people don't access these websites unless they or their family members are diagnosed with the condition. The information is very basic.

Cancer treatment:

Reflections: Various kinds of treatments (Chemotherapy, Immunotherapy, Hormone therapy, Radiotherapy, Surgical Oncology) are well explained- what is the treatment? How it works? What are the side effects? What are the modes of administration? What are the precautions? How to manage the side effects?

These are generic content, and the information is compartmentalized but it is not put into context with real stories.

Clinical research:

Reflections: This section has information for cancer patients to help and contribute to the ongoing testing of medication and some numbers are provided for contacting the research group.

Oncology Quebec:

Reflection: As the name suggests, this is for the support of residents of Quebec which was last updated in 2018. This is outdated as the developments in cancer are fast paced and this section was not further analyzed.

Living with cancer:

Reflections: This section talks about self-care, and beauty tips for feel-good factors that are explained but quite enough to take it from the information that is provided on the website.

Life habits:

Reflections: This talks about a balanced diet, exercise and rest that everyone has to follow for a healthy life, but it is good to have a section as a reminder for the patients.

The shock of the diagnosis

Reflection: This section has a small paragraph to deal with mental well-being. There is a contact number and email to connect to for further assistance.

Cancer therapies that complement cancer treatment

Reflections: The complementary therapies and their benefits are mentioned in a paragraph with a number and email.

Parenting with cancer:

Reflections: This section has a brief description of being a parent with a diagnosis of the disease. How things can be communicated to the children. A worthwhile section that can be expanded further and there are contact details.

Being a caregiver:

Reflections: This section was not divided into

Information on different stages of non-small cell lung cancer on the website:

<https://cancer.ca/>

The informal is broken down well for cancer for stage I to IV. These are in bullet points but the way the information is laid out is more accessible compared to <https://cancerquebec.ca/>.

The landing page of the website is confusing with all kinds of juxtaposed information. Accessing the information from the burger menu is a lot more organized but each time the subsections are accessed it is hard to go back to the section from where we began. This can be frustrating for the user experience. For information online, it is the way things are organized for accessibility that comes first, and this has to complement the content.

Under types of cancer - neither Anaplastic Lymphoma Kinase Positive, nor small-cell lung cancer were listed on the website. The term “Lymphoma” showed up in the search engine. In the global search on the website “Treatments for recurrent non-small cell lung cancer” showed up. This gave an overview of the condition, but no in-depth information and it was last reviewed in 2020.

In the global search on the website, three links showed up for ALK-positive- 1) Targeted therapy for non–small cell lung cancer 2) Treatments for recurrent non–small cell lung cancer 3) Treatments for stage 4 non–small cell lung cancer. All the areas have generic information that gives a holistic view of the condition.

Synopsis of ALK-positive on Wikipedia:

https://en.wikipedia.org/wiki/ALK_positive_lung_cancer

Abnormal gene fusion of echinoderm microtubule-associated protein-like 4 with anaplastic lymphoma kinase that produces the protein that triggers and maintains the malignant behavior of cancer cells. The link also has signs of symptoms with incomplete sentences as bullet points. There is mention of adenocarcinoma and median age of 50 years. Brief screening methods are mentioned that are standard in the USA and Canada. The immunotherapy drugs are listed and some generic information on the prognosis. Old information from 2018 is listed as 6.8 years of median survival. This information is six years old and has not been updated.

Synopsis of ALK-[positive.org](http://ALK-positive.org)

This is a patient-driven organization that supports patients around the world. It is one of the authentic, reliable sources of information on community engagement platforms. This is an excellent ALK-positive specific group with free second opinions with ALK doctors, oncology directory experts, invitations to summits and events, being aware of research, trials, testing programs, members map to connect nearby and future fundraising to this specific condition.

The statistical data shows that ALK-positive accrues 5% out of all lung cancers, 30% are diagnosed under 40 years, 50% are under 50 years, many are in their 30's and 40's and some are in their teens and twenties. It was discovered in 2007 and the description is similar to the Wikipedia description mentioned above.

The media section has blogs, newsletters, prospects, annual reports, and fund a rising toolkit.

The blog section has a series of patient spotlights with interviews with questions ranging between 3 to 5 that give an overview of their journey of the condition. The blog posts are mixed with a combination of conversations with doctors and recipes of food by ALK-positive patients.

One of the most reliable and up-to-date websites has information that touches upon many areas with authenticity but with a holistic view, that makes it generic. It touches

upon the lived experiences of individuals but the sharing of them is structured and choreographed.

The website covers various aspects ranging from the symptoms, diagnosis, stages, life expectancy/ prognosis, surgery, medications, traditional therapies, alternative/ adjunctive treatments, treatment recommendations, side effects of medications, resistance to the medication, second opinions, remote consultation, costs, patient testimonials, ALK-positive summit, ALK+ALKs (ALK talks) sessions. The information is compartmentalized, and this leads to how can the condition be mediated where various aspects are encapsulated to bring awareness of the condition, care and cure of ALK-positive through 'thick description'

Analysis of [cancer.Net](#)

Reflections: The website clearly shows that information is closely monitored by the editorial board and each section has a certification of the year in which the content was last updated.

The navigation bar has- types of cancer, navigating cancer care, coping with cancer, research and advocacy, survivorship, blog and about us.

For the scope of analysis 'types of cancer' section and 'blogs' will be covered. The quality of the content is informative, detailed, structured, organized with a flow and

simple to read. There are supporting images and videos in some parts, if not in all the areas.

Types of cancer: The red box in image 01 has a list of common cancers or has sections A-C, D-H, I-L, M-Q, R-Z and it is easy to go to any type of cancer. This makes it easy to look at a small list rather than scrolling through an index from A-Z. Reduces the time in searching.

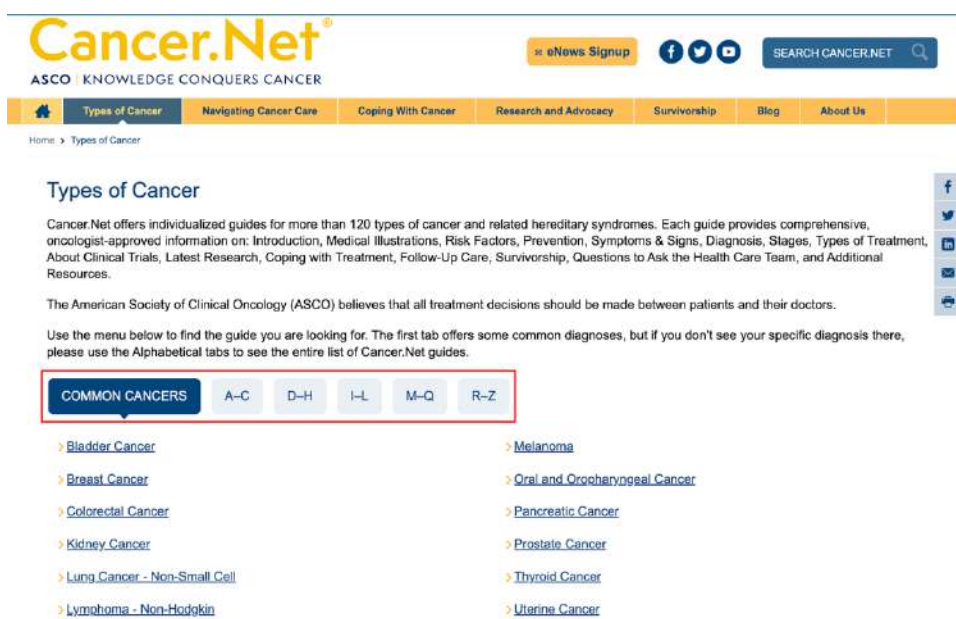


Image.57

When a type of cancer is selected- in this case non-small cell lung cancer, it opens to a list of icons with words supporting it. This makes it easy to skim through various sections that the reader wants to access.

Note that the main navigation bar remains the same.

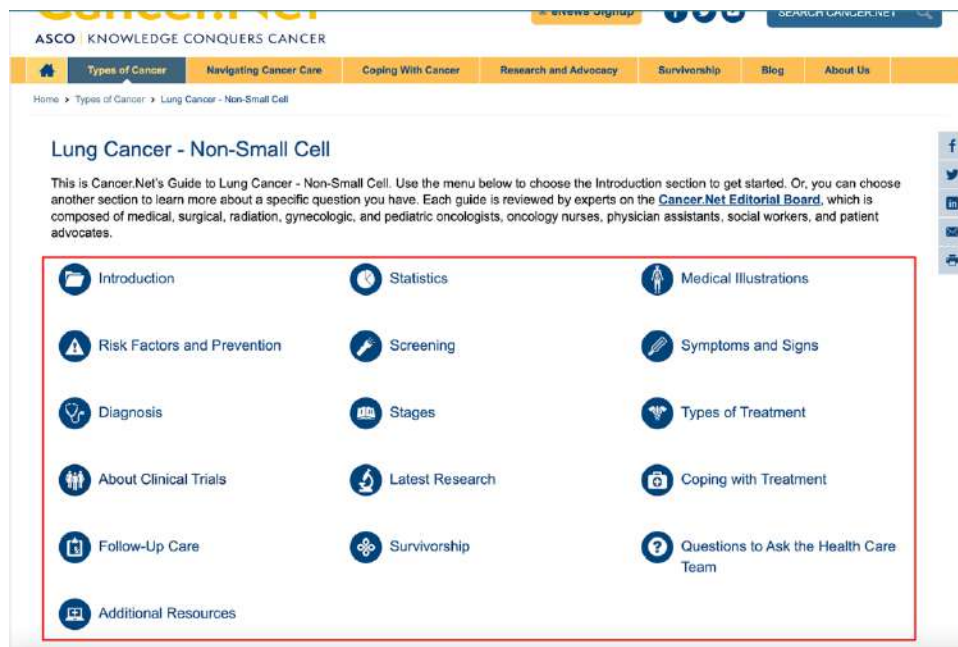


Image.58

When any section is clicked, the list moves to the left side so that the user does not have to go back but can access all the sections from the same page. It is easy to go back and forth.

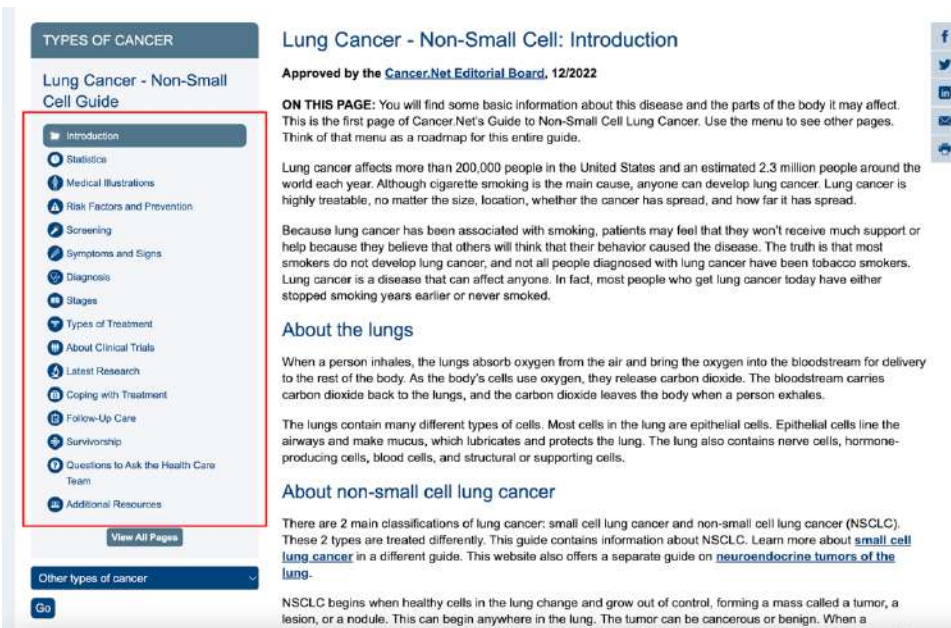


Image.59

The most interesting part is the 'view all pages' button, which has an enormous advantage because it puts all the content that is categorized in different sections into a single scroll page. This reduces the number of clicks and also gives an overview of the entire content about non-small cell lung cancer. This gives a seamless reading and a holistic view of the content.

TYPES OF CANCER

Lung Cancer - Non-Small Cell Guide

- Introduction
- Statistics
- Medical Illustrations
- Risk Factors and Prevention
- Screening
- Symptoms and Signs
- Diagnosis
- Stages
- Types of Treatment
- About Clinical Trials
- Latest Research
- Coping with Treatment
- Follow-Up Care
- Survivorship
- Questions to Ask the Health Care Team
- Additional Resources

View All Pages

Other types of cancer

Go

Lung Cancer - Non-Small Cell: Introduction

Approved by the [Cancer.Net Editorial Board](#), 12/2022

ON THIS PAGE: You will find some basic information about this disease and the parts of the body it may affect. This is the first page of Cancer.Net's Guide to Non-Small Cell Lung Cancer. Use the menu to see other pages. Think of that menu as a roadmap for this entire guide.

Lung cancer affects more than 200,000 people in the United States and an estimated 2.3 million people around the world each year. Although cigarette smoking is the main cause, anyone can develop lung cancer. Lung cancer is highly treatable, no matter the size, location, whether the cancer has spread, and how far it has spread.

Because lung cancer has been associated with smoking, patients may feel that they won't receive much support or help because they believe that others will think that their behavior caused the disease. The truth is that most smokers do not develop lung cancer, and not all people diagnosed with lung cancer have been tobacco smokers. Lung cancer is a disease that can affect anyone. In fact, most people who get lung cancer today have either stopped smoking years earlier or never smoked.

About the lungs

When a person inhales, the lungs absorb oxygen from the air and bring the oxygen into the bloodstream for delivery to the rest of the body. As the body's cells use oxygen, they release carbon dioxide. The bloodstream carries carbon dioxide back to the lungs, and the carbon dioxide leaves the body when a person exhales.

The lungs contain many different types of cells. Most cells in the lung are epithelial cells. Epithelial cells line the airways and make mucus, which lubricates and protects the lung. The lung also contains nerve cells, hormone-producing cells, blood cells, and structural or supporting cells.

About non-small cell lung cancer

There are 2 main classifications of lung cancer: small cell lung cancer and non-small cell lung cancer (NSCLC). These 2 types are treated differently. This guide contains information about NSCLC. Learn more about [small cell lung cancer](#) in a different guide. This website also offers a separate guide on [neuroendocrine tumors of the lung](#).

NSCLC begins when healthy cells in the lung change and grow out of control, forming a mass called a tumor, a lesion, or a nodule. This can begin anywhere in the lung. The tumor can be cancerous or benign. When a

Image.60

From the same page, other types of cancer can also be accessed. The tab has a drop-down menu to pick up any kind of cancer. The user does not have to click on the 'types of cancer' from the main navigation bar and go back to a different page.

The image below shows the dropdown window

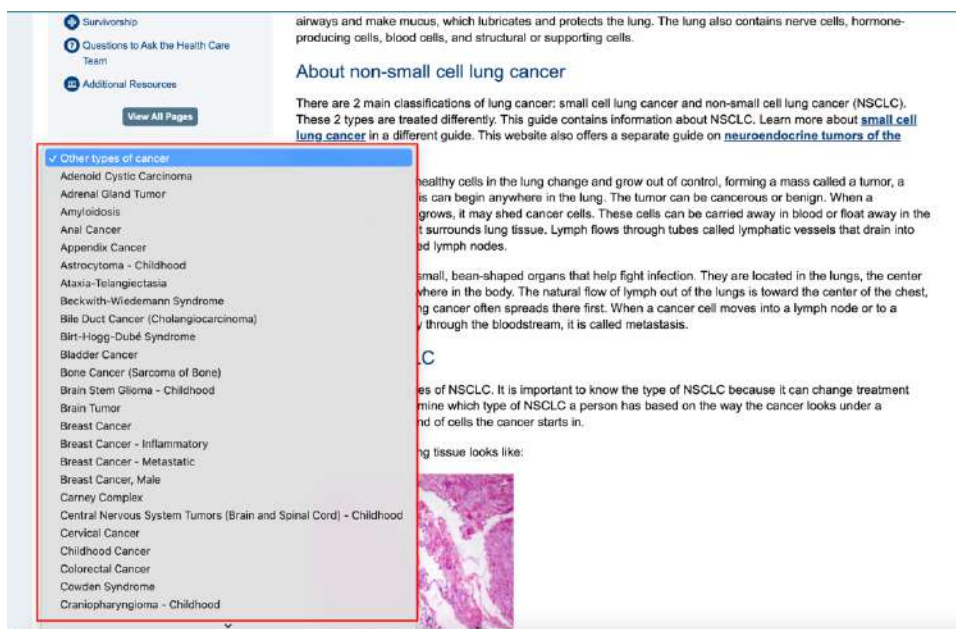


Image.61

The Blogs section has a dropdown window from which the users can access various topics of interest. Usually, the other assessed websites do have an organized blog section. It is juxtaposed with different kinds of articles, and it is not curated or organized in the manner in which this website has been designed.

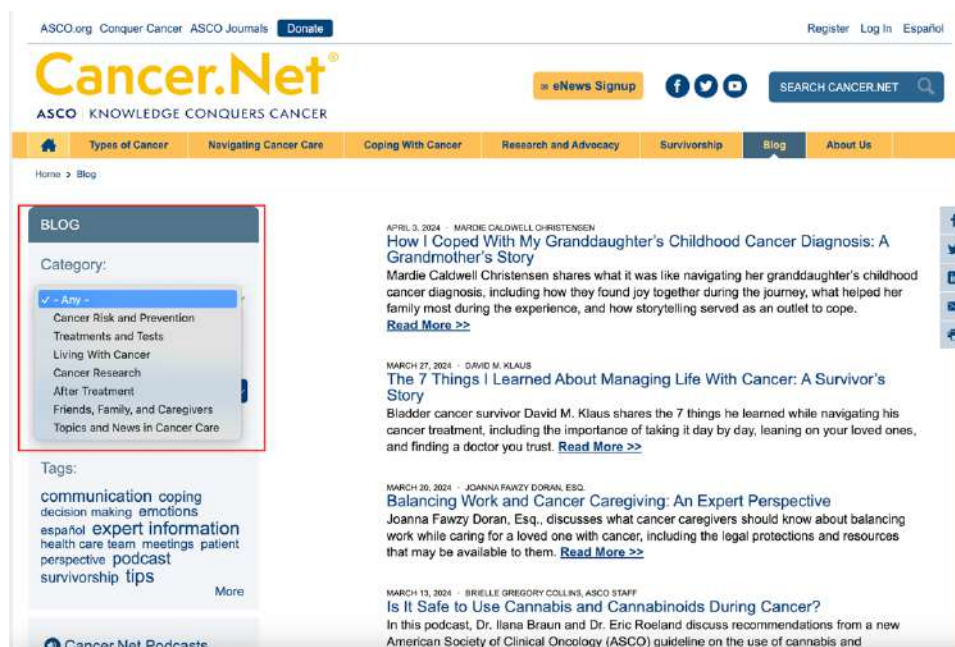


Image.62

The interesting feature is that the blogs can also be accessed based on the year. Older posts can have redundant information as developments in cancer care have been advancing at a fast pace.

There are options to select the articles by adding tags, which is also an interesting feature. More tags can be added but the default tags cannot be deselected. This is one negative feature.

Character observations

Here is an example of Linda, who came in the morning at the right time when breakfast was served, which aligned with the regular cleaning session in room no 1945. I saw Linda only once in the day. Her job was to collect blood samples. It was not one tube of blood, but she had to collect over five tubes. She would enter the room with earbuds, and it always felt like she was talking to me but would have a conversation on her phone with someone on the other side. She would seamlessly switch from her conversation to wishing me and would continue her phone talk. I have not seen a single day for three weeks where she came with the same hairstyle. Her earring color always matched her uniform. One day, I saw the colorful striped earrings she wore. I thought to myself that she had finally had a mismatch. On close observation, one color in the earring matched her uniform shade. The description above is about the choice of her appearance and a brief description of her mannerisms. But she was a multitasker with perfectionism. Drawing blood need to poke the needle into the arm which felt like an ant bite. When she pricked the needle, there was no uneasiness. Linda had mastered her work with precision and did her job daily while talking over the phone. Everyone working at the hospital never stressed themselves. Even if they were under pressure, it never showed on their faces because it could affect the patients. Linda represents the calmness of the environment. She worked in a stressful environment. Her job was to push the cart, filled with tubes, both empty and filled. She would then look at the inventory and cross-check the wrists of the patients. Then she drew the blood. Sounds

simple, but the number of tubs of blood depended on the number of tests the doctor would prescribe. She had to be alerted all the time and could not make mistakes. It is a monotonous repetition of what she did, but patients could be of varying conditions and temperaments. Handling the unpredictability of patients' temperament requires caution. The way I saw Linda- while painfully recovering from the phenomena was that she reduced her stress by taking care of herself. By doing so, it felt like it was a meditative process for her. She broke her monotony by self-appeal, made herself presentable, and this motivated her to do her work, that was mundane.

The oncologist Dr. Florescu is another example of the motivation and energy she has in her. Dealing with patients in the darkest period of life is not easy. Doctors are up to date with their knowledge relating to their expertise. Cancer treatment is dynamically changing, and they (doctors) know how to handle the situation with the knowledge gained over a period. Their experience cannot tell the efficacy of individual bodies respond to the cancer treatment. Only observation can let them know the path they have to take in finding the best possible treatments. Nothing was ruled out. Unless and until- every aspect was investigated with precision. The organs in the body do not stand alone but work together and metastasized cancer cells means that they take over the performance of the body, causing domino effects. They (doctors) have the responsibility to manage these unruly cells. The doctor can do their work by giving their professional expertise, but Dr. Florescu has mastered the art of handling the patients by creating a positive vibration around. The sessions with her were full of gags and laughter that half

the cancer cells would get destroyed by talking to her. In one of the early conversations, she asked if I had children, and my response was a single daughter. She immediately replied by saying she had five children, which is quite a challenge. I bounced back when she said that all her children were boys. I could not resist telling her that it was hard for me to handle a single girl child. How could she manage five boys? The nurse giggled in the background. The picture that I got in my mind was five boys creating chaos and she was in between, pulling her hair and screaming. It was easy to visualize this, as I grew up with a brother. We both (my brother and I) did not make life easy for our mother who was working full-time and had a strong profession. I was not sure if this imagery I got in my mind was true, but this is how my brother and I would put our mother in a tight spot. If she knew how to handle rogue cancer cells in the patient's body, it would have been quite easy for her to take control of half a dozen boys (including her husband). By the end of the day, the conclusion was that she lived in pleasant chaos. With all this she had the art of healing the patients with her presence.

Publishing the content

The work has been presented to publishers in India and they are interested in printing the book for nonprofits. The selling price of the book will cover only the printing cost. Although the treatment for ALK-positive is making a strident development, the documentation and certain processes can get redundant in a decade. What works in favor of the printed content is the detailed nature and the human experience that one goes through emotionally. This can never change. Regardless of better developments

and facilities, getting diagnosed with cancer is a shock in life that one cannot get interns with it. Unlike other cancers, ALK-positive happens to healthy individuals who have followed strict regimes in maintaining their bodies. It is common to go to bed in the night and ask 'Why did I get this' and the same question can reappear when waking up in the morning. Sharing stories like this will only answer the 'why' and the answer is that 'I am not alone'. 100,000 people are affected by it without a cause and revisiting the book and flipping the pages like any other graphic novel only help motivate the ALK-positive community to put their condition and move on with their lives, while the medications (various kinds of treatments in combination) will do its job.

Online accessibility of the content

The digital copy of this graphic novel will be accessible online and can be downloaded for free. The goal is to make this content accessible to people across the world. As mentioned earlier, the story is about my experience of being diagnosed with cancer as an international student at Concordia University. It describes the various teams working within their systems and collaborating with other groups or systems within Montreal, Quebec. The accessibility of this online content opens doors to the rest of the world to know the support I got as an international student, which the government of Quebec provided. This is regardless of the status of being an international student and the medical system maintained to give the same privilege as it's on citizens. It is a sheer coincidence that the timing of my diagnosis aligned with my studies at Concordia University. It is also a coincidence that the area of the research I am focusing on is

social design. This alignment was an opportunity to combine all these convergences to show to the world the efficiency of the government of Quebec. It should take pride in supporting various systems. Research-creation in my self-realization, puts research through design in its optimal capacity to create its identity. The combined aspects can be made visible if the content is accessible online.