

Oncological Disease Narrative: Analysis of Masculinity Aspect in Men's Experience Stories

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Abstract. The aim of the paper is to clarify the narrative of oncological disease in men's experience stories and to analyse the masculinity aspect in them. The theoretical part of the work consists of the study of the sociological and anthropological aspects of the illness, the definition of the illness narrative, contextualizing all of this with theories of masculinities. The data has been collected through narrative interviews with men who have an experience of oncological disease. A narrative approach and psychoanalytic criticism were used for the analysis of the collected data. The men constructed their illness-related experiences through the prism of masculinity, with a particular focus on changes in the body and masculine identity.

Keywords: narrative oncology, illness narrative, masculinity, psychoanalysis

Introduction

Man is always expected to be strong, and to be able to overcome all life's challenges and remain tough. As a result, every man must constantly demonstrate these qualities and prove them to others. Society expects that a man will be the one to overcome any challenges in life and be able to cope with any kind of difficulties. Men are subject to specific requirements which they must accept and perform 'by default'. This leads to the formation of misconceptions and misperceptions of gender roles. This is particularly evident when it comes to men's health. Oncology itself is considered a taboo subject in society and public discourse. Consequently, there is very little open communication on this topic in the public domain. In the context of a growing number of campaigns to promote public awareness of oncological diseases and their potential risks, it can be argued that the topics, which are not openly discussed in public, and which are considered sensitive, are being highlighted and attempts are being made to actively communicate about them.

Statistics also show that only one in four men in Latvia who should have had PSA tests last year for health monitoring and early diagnosis of prostate cancer have had these tests. Experts point out that this is often due to misunderstood masculinity (Zvirbulis, Eglite 2022). This is also well demonstrated in the context of the Covid-19 pandemic: a recent study confirms that men are less likely to wear masks and take precautions. The reason for this is that men are more likely to feel a stigma from wearing a mask, as it tends to be interpreted as weakness (Mahalik *et al.* 2022).

At the global level, there is a fair amount of research on gender and disease, trying to explain the experience of illness from a sociological and anthropological perspective. Gender research is also quite active in this aspect, offering alternative perspectives on both people's experience of illness and the lived experience of illness. However, it has to be stated that the narrative approach has rarely been used on this perspective. It can be argued that there is a need for empirical data that can reflect the current situation in society and explain the social aspect of illness through subjective narratives. There are several sources of statistics regarding the current situation in society, i. e., how many are ill, and how many are dying. However, there is almost no data on the ways how everyone – in the context of this work, a man in Latvia – experiences and copes with this challenge. Only through the stories it is possible to gain an understanding of life events, as statistics only offer aggregated data, which primarily give a generalized understanding of the problem.

Even though theorists have largely focused on the interaction between masculinity and disability and the ways how, for example, a disability or chronic diseases affect masculinity, it is possible to argue that the situation tends to be similar regarding cancer. Thus, men could operate with similar patterns, as cancer tends to radically change the course of life and a person's well-being in a short period (Miller 2004, 349–351). Other sources also argue that the threat to masculinity associated with cancer is amplified for those who occupy a traditional and restrictive masculine gender role. Cancer-related masculinity risk can be characterized by feelings of loss, diminished significance, or hopelessness (Wei-Ting Wang *et al.* 2020).

Hence, the aim of the study is to clarify the narrative of oncological disease in men's experience stories and to analyse the masculinity aspect in these narratives.

For this purpose, three research questions have been formulated, to which answers are sought during the study:

- How is the narrative of oncological illness constructed in men's accounts of their experiences?
- How does the disease affect men's perceptions of their masculinity?
- How is masculinity represented in the stories?

Methodology

The methodology has been devised with the view to achieving the aim of the study, i. e., clarifying the narrative of oncological disease in men's private stories and analysing the aspect of masculinity in them. Meanwhile, the study aims to provide clear answers to the research questions: how oncological disease is communicated in men's experience stories and how does the disease affect men's perceptions of their masculinity, as well as how is it reflected in the stories. For this purpose, a qualitative approach was chosen for the implementation of the research. Consequently, 8 narrative interviews were conducted with men currently experiencing any oncological disease or being in remission, because, after studying the theory, it was found that these men could not be considered 'completely cured' (Frank 1997, 10). To reach the target group, the author communicated with support groups, societies, and associations assisting and supporting cancer patients. Almost all the informants were recruited through support group leaders, for example, 6 participants were recruited from 3 different support groups, organizations, and associations.

At the same time, the author of the study wrote an online invitation to participate in a study about a person's experience with cancer, guaranteeing confidentiality and anonymity. This communication tool was used to obtain two more informants. Later, the data collection process followed the principles of narrative interviews, asking the men to share their experiences of the disease from the beginning, and inviting them to say anything that came to mind, even if they felt it was unrelated to the topic. During the interviews, the researcher listens carefully and follows the informant's story, asking clarifying questions if necessary. Additionally, questions were asked about defining and experiencing masculinity during illness. During the interviewing process, the author of the study conducts the informants' observations. The author traced the occasions when the interviewees were silent, as well as recorded non-verbal expressions of the body; the transcripts of the interviews also represent any over-statements and repetitions of words and sentences. Once the necessary data was collected and transcribed, the narrative themes were identified to understand what constitutes a narrative of oncological disease. In addition to the thematic analysis, a performative analysis was carried out to understand how masculine identity was constructed and expressed in the narratives.

To analyse narratives, A. Frank's approach was used, which is based on the types of illness narratives defined by himself, which are common in chronically ill people. These are the restitution narrative, the chaos narrative, and the quest narrative (Frank 1997, 73). Frank's typology of narratives has been used in studies of adults' experiences of cancer, HIV/AIDS, and chronic illness. These studies reveal the complex ways in which social and cultural narratives shape

the meaning of illness for patients. Although a single narrative is primarily dominant in accounts of patients' experiences, a single individual may draw on different elements of each narrative simultaneously or over time (Roher *et al.* 2017).

After the narrative analysis, Lacan's structuralist psychoanalytic approach was used to analyse the texts. He broadened the focus of psychoanalytic criticism, which sought to define the literary text simply as a simulacrum of the unconscious for diagnostic evaluation. In his view, the literary text is a conscious articulation, an artifact and a fictional product, and it cannot represent the unconscious without mediation. The literary text acts as a field where the unconscious desire is reframed. Desire lies in the text as a motivating force that is the whole of literary creation process, its aesthetics and even its reading (Azari 2008). In his theory, the psychoanalyst has defined 3 main stages: the real (*réel*), the symbolic (*symbolique*), the imaginary (*imaginaire*). The *imaginary* refers to the world of sensory impressions, images (dreaming, fantasizing, identifying), which strongly attracts and are not real. It is based on sensuality, it is organized in a dual and imaginative way, determines narcissism, identification and thus the ego formation. It manifests itself in the seduction, vanity, alienation and deception of the subject. The *symbolic* includes everything that, in the broadest sense, refers to language; the symbolic refers to the signifying order, the signifiers in language that defines the subject; it refers to the unconscious and the intellectual. The *real* is Lacan's dimension that is the most difficult to identify, because it is "that which cannot be said or thought of and which seems alien and threatening precisely because it has no relation; the real manifests itself, for example, as trauma, panic, sexuality and death" (List 2014, 159). The Lacanian approach involves the analyst – in this case, the researcher – listening and following the informant's story and pays attention to the use of language, especially the signifiers which are defined as words that are devoid of direct meaning. This helps to define and reveal their duality, which is the carrier of unconscious meaning. As it has already been pointed out, dreams, mistakes, and misstatements, as well as the choice of the 'wrong' words are of interest to psychoanalysis (List 2014, 162).

This methodology enabled the author to identify the ways how masculinity and the related identity are manifested. In addition to this, the author also drew attention to atypical language use: overstatements, metaphors, and silences. Here, the author points out the fact that he does not claim to be a psychoanalyst, but the literary research approaches were used to analyse the text.

Results

To summarize the data from the men's narratives, it can first be argued that men construct a narrative of both their experience of oncology or illness and, in parallel, men construct a narrative of their masculine identity that is

threatened, reclaimed, lost, and reformulated during illness. Thus, in men's stories, the construction of the experience of illness and the construction of the challenges of masculine identity are parallel. Therefore, 2 major thematic categories of narrative can be crystallized: the aspect of the illness experience and the aspect of masculinity.

1. Themes permeating the oncological narrative

Overall, it is possible to recognize themes that run through several of the stories and that can be seen as central and constitutive of oncological disease. These themes are information-seeking, treatment, fear, reframing the relationship with the body, alternative treatments, criticizing doctors, changes in the body, regaining masculinity, threatening/losing masculinity, self-realization, and remission. Clearly, the analysis revealed several other themes, but the author identified them as pervading – occurring in almost all of the stories.

Oncology becomes a daily practice that men must accept, and cope with specific things – examinations, treatments, and trying to share experiences. It should be noted that for men currently in remission, the story also ends with self-identification in this condition. However, remission does not mean recovery for almost any of the participants of the study, because of the fear associated with the possible return of disease. At the same time, the treatment narrative is shaped by the informants' experience of chemotherapy or radiation, to which the men themselves attribute a symbolic meaning, because it is related to the changes in the body and hence, masculinity. These aspects of the story are more narrative than, for example, the aspects pertaining to surgery or medicine they took. Thus, the surgery and the story about it remain untold, and this can be linked to the routinization of experience in the narratives. It means that aspects such as doctor's appointments, medication, or surgery lose their importance in the men's stories, being replaced by those things that are more threatening to the identity and especially – masculine identity. Those aspects the research participants themselves try to tell in a very unemotional way permitting to distance themselves from the experience.

The second important point revealed by the narratives is masculinity. Men both understand and construct the experience of illness by emphasizing what happens to their masculinity and especially to their bodies. Sociology professor Arthur Frank has asserted that the narrative of illness is not only a man's story, but also the body's story of what is happening to it. It is possible to point out that the body is another narrator, but its story is told by a man. Men hardly focus on the emotional aspect and do not talk about it. Men reflect on their experiences, but the emotional and sensual aspect remains untold. Even when men construct stories about vulnerability and their inability to perform masculinity according to their beliefs about it, they do so in a highly masculinized way and accentuate

other obstacles of the experience. On the one hand, this could be interpreted as a desire to perform the masculine identity, as nearly in every story the men emphasized it, even if that masculinity was threatened or the men constructed the experience of illness through the loss of masculinity. In every story, however, masculinity – and especially the bodily aspect – constituted a pervasive motif.

It is significant that the participants of the research do not include private space in their narratives of experience, i. e., they do not describe how, for example, their closest ones felt, how their relationships with friends, relatives, or children developed in general. This is an important point, because each informant in the study has a family. From the acquired data, it can be concluded that close people are not even participants in the story, as they are hardly ever mentioned or serve as attributes of the narrative rather than as characters. Even though the private space remains outside the story, the informants' narratives are very personal, and therein it is possible to trace both the ways how their identity has changed and how the crisis of masculinity is developing.

Importantly, the men were open about their sexual dysfunction caused by the disease. The key point is that each man's story is not only about changing his identity and accepting oncology as a social practice, but it is also a story about his own body. Each informant emphasized the bodily aspect of the narrative. As already mentioned, the construction of experience is linked to the physical changes of the body. The informants' narratives were the field in which masculinities were constructed, reframed, and reformulated. Consequently, it can be established that the narrative of oncological illness merged with the narrative of masculinity, mostly with its alteration. The body is the most important aspect of masculinity, and the body has been given a symbolic significance, as the body helps to maintain and affirm masculinity. The explicitly constructed experience of illness is also influenced by the state of the man's health or the social context in which the story is told. Men who are currently in remission construct a quest narrative, trying to emphasize what the experience has given them and what they have gotten out of it. However, for those who have an undetermined oncological status or are going through the disease now, the stories are different because the narrative shows the chaos aspect; the story is about what they are going through here and now. Men currently in remission, on the other hand, tend to look back on their experiences.

2. Psychoanalytical view on the men's narratives

Using Lacan's psychoanalytic approach, it was also possible to identify how the men's narratives, i. e., their language, express unconscious desires and fears. The author proposes that the real, or what cannot be expressed in language at all and exists outside it, is the masculine identity of men, or the core, which also influences the ways how the symbolic and the imaginary function. This is

the basis for identification and the means how the story was shaped and taken forward. The real is expressed in the fear of losing the normativity of the body. The imaginary for the men is mostly expressed in the episodes in which they talk about their masculinity before the illness, as well as in constructing a narrative about their bodies.

It could be argued that the men in the story form an opposition: me-before-illness/me-now. Consequently, the narratives construct an image or a discursive field that is free from illness and that serves as an affirmation of masculinity. This juxtaposition helps to structure the understanding of masculinity and serves as a kind of anchor that also helps to structure the narrative and to emphasize the bodily aspect and the changes in it. Here it can be further inferred that men are no longer narrating about themselves but making references to their symbolically constructed image. The story of oneself before the illness is no longer a story about oneself, it is a symbolic representation of one's own image that helps the narrator to affirm what he has been. The "I" in the stories becomes a subject that only expresses and sublimates what is currently unavailable to the narrator. The narrator probably derives pleasure from this, creating a masculine image that is currently unavailable because of the disease.

The last point, which is structured in language, is the symbolic concept. It can be argued that this concept is related to both how men construct their image in the story, or how they express the identity that currently prevails, and how they want to see themselves, as well as how they try to reclaim masculinity, or, on the contrary, how they reformulate it to fit those concepts. The symbolic aspect is mostly linked to men's desire to regain the masculine identity they had before the illness. This is manifested in the episodes where men construct a masculine post-illness identity, either by reformulating it or symbolically reclaiming it.

Conclusions

Oncology is a major challenge to male masculinity: the experience of cancer is closely linked to it. Men's stories deal with moments of threat to masculinity. Men try to reformulate their masculinity when they realize that they will no longer be able to perform it or no longer meet the demands they have placed upon themselves. Masculinity for men is closely linked to the normative body, consequently, the greater the changes, the greater the perceived threat to masculine identity. The men in the story also construct a masculine image of themselves that they had before the illness, which they also contrast in the story with the one they had during the illness. It can be stated that men strive to maintain masculinity, which becomes a central aspect in the narratives of oncological disease. Thus, even in narrating their experiences, men attempt to reframe that masculinity through language. This is evident both in the topics chosen, i. e., what is being narrated,

and in the way the topics are narrated. The symbolic loss of sexual power is clearly a traumatic and difficult moment for men, which affects the understanding of masculinity. Hence, men need to reformulate their understandings of this, otherwise they may feel the stigma that they impose on themselves. Men make up a highly masculinized story of oncology. That is, they include only those aspects that could stereotypically be considered masculine. The psychoanalytic approach suggests that men's understanding of illness is based on masculinity and that men's narratives of illness are mostly about the desire to reclaim masculine identity. The participants of the study continuously referred to a symbolically constructed masculine image of themselves before the illness, which they wanted to regain or realized that they would never recover. It can be hypothesized that the masculine identity is what determines how the story will be told.

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REFERENCES

- Azari, E. (2008). *Lacan and the Destiny of Literature: Desire, Jouissance and the Sinthome in Shakespeare, Donne, Joyce and Ashbery*. London: Continuum International Publishing Group.
- Frank, A. W. (1997). *The Wounded Storyteller*. Chicago: The University of Chicago Press.
- List, E. (2014). *Psychoanalyse*. 2. Aufl. Stuttgart: Ebner und Spiegel.
- Mahalik, J. R., Bianca, M. D., Harris, M. P. (2022). Men's Attitudes Toward Mask-Wearing During Covid 19: Understanding the Complexities of Masculinity. *Journal of Health Psychology*, 27(5), 1187–1204. DOI: <https://doi.org/10.1177/1359105321990793>
- Miller, A. S. (2004). Coming to terms: masculinity and physical disability. In Kimmel, M. S., Messner, M. A. (eds). *Men's Lives*. Sixth edition. Boston: Pearson A and B, pp. 345–366.
- Roher, S. I., Gibson, J., Gibson, B. E., Gupta, A. A. (2017). Listening Through Narratives: Using a Narrative Approach when Discussing Fertility Preservation Options with Young Cancer Patients. *Current Oncology (Toronto, Ont.)*, 24(1), 10–15. DOI: <https://doi.org/10.3747/co.24.3419>
- Wei-Ting Wang, A., Hoyt, M. A. (2020). Cancer-Related Masculinity Threat in Young Adults with Testicular Cancer: The Moderating Role of Benefit Finding. *Anxiety, Stress & Coping*, 33(2), 207–215. DOI: <https://doi.org/10.1080/10615806.2020.1713447>
- Zvirbulis, Ģ., Eglite, D. (2022). Vīrs un... vēzis [Man and... cancer]. *LSM.lv*. Retrieved from: <https://www.lsm.lv/vezis/stasti/virs-un-vezis>