

The Fairy Tale as a Time Machine in Palliative Care

Eva Bojner Horwitz[†] and Natalia Tolstikova

Department of Clinical Neuroscience, Karolinska Institute, Stockholm, Sweden

[†]Corresponding author: Bojner Horwitz E, Department of Clinical Neuroscience, Karolinska Institutet, Norra Stationsgatan 69, v 7, 113 64 Stockholm, Sweden, Tel: +46705863694; E-mail: Eva.bojner.horwitz@ki.se

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Abstract

Background: Studies show that certainty of death may affect time perception and the meaning attributed to time. The central interest of this research is the connection between the perception of time and fairy tales. The aim of the study was to explore the fairy tale method in their delivery of palliative care and how this work is related to the concept of time.

Methods: A focus group interview conducted with a team delivering the service in Russia forms the basis of the exploration of experiences of working with a fairy Tale method in palliative care. The data generated from the focus group are analyzed using a phenomenological-hermeneutic method. This involves reading the data at three levels: naïve reading, structure analyses and complete interpretation.

Results: From the analysis, it emerged that the fairy tale method relates to 1) a multidirectional time continuum 2) an intensification of the perception of time and 3) the alertness of time. Together, these three themes act together to form a "time machine" which regulates both the perceived speed at which time passes, awareness of the quality of time, and the intensity of the perception of time within the fairy tale.

Conclusion: The 'fairy tale method' promises the possibility of transforming the experience of time for hospice patients, helping them to mediate perceived time and calibrate awareness. The findings are discussed with regards to the potential applications of the fairy tale method as a time machine tool beyond palliative care: It is suggested that it could be extended into a more existential instrument that might help larger population to deal with the postmodern living conditions and extreme hurriedness.

Keywords: Chronos; Fairy tale; Health care; Kairos; Phenomenological hermeneutic; Stress; Time factor

Background

Gnezdilov [1], Professor of psychiatry of the St Petersburg Medical Academy, works with dying patients. In 1990, he opened the first hospice in Russia that included practices of palliative medicine [2]. Most hospice patients are in the final stages of oncological diseases and are without hope of recovery. In palliative wards, death is considered a part of the natural cycle of life, and attempts are not made to slow it down the dying process, nor "sped it up" by artificial means. Through the care that they provide, hospices help a patient to find value and meaning in their lives at the very moment when one may seem to have lost everything [2]. In addition to enacting the common principles of biomedical medicine, in the hospice, Gnezdilov [1] practices several forms of art therapy. The dimensions of pain are complex and interrelating, but we might nevertheless appreciate that whilst a physical pain can be alleviated through medication, a psychological one can have several components –social, emotional, and spiritual [1] – and requires alternative methods with which to relieve it. One method developed by Gnezdilov [1] to approach this problem is the therapeutic fairy tale.

The idea of using fairy tales in palliative care was hit upon accidentally when Gnezdilov [1] attended to a dying six year old who asked him to tell a story; while recounting to him a fairy tale about a

prince, Gnezdilov [1] witnessed the boy die with a smile on his face. At a fundamental level, the Fairy Tale method or 'FT' method, discussed in this study consists of the telling of Gnezdilov's [1] fairy tales as tailored to individual patients. Tales may be told with or without singing, the accompaniment of music instruments (i.e., guitar, drums or bells), and sculpture making [3]. According to Gnezdilov [1], based on his experiences fairy tales help patients to mediate on their problems and on necessary end-of-life affairs by immersing themselves in symbolic worlds. During this immersion, patients appear able to "switch on their internal resources" to find within themselves solutions that only that person is able to come up with, that is, nobody else in the world, including a psychotherapist, knows in advance what this solution could be [4].

Traditionally, fairy tales were told in a pre-scientific attempt to find answers to the fundamental questions about human life [5]. Fairy tales often have their roots in mythology: myths are known to be vehicles for the establishment of order within a culture; of understandings of morality and of rules for conduct in face of challenges [6]. They, like fairy tales, are built on the experiences of past generations, serving to create archetypes of those difficult situations and their solutions. On some level, therefore, these stories act as heuristics [7]. Fairy tales have been a source of education, a mode of communicating, symbolically, sets of social rules and cultural traditions [8].

Parkinson [9] writes about therapeutic stories that have ability to change minds and even bodies. His assessment can be applied to fairy

tales, stories of magic and mythical heroes, rich in symbolism and metaphor. Fairy tales became a tool of folk psychotherapy before psychotherapy became a profession [8]. In modern times, fairy tales have been used in pedagogy and therapy on the basis of their ability to facilitate the discovery of new perspectives on a problem and therefore unforeseen solutions. In this way, fairy tales can be said to be able to “sneak” into the conscious mind [9]. The advantages of fairy tales go beyond their ability to enhance daydreaming: Fairy tales foster the painting of multisensory pictures in the mind of the listener, allowing patients to move their attention away from their external reality toward an imagined world [10-15]. The way in which people imagine their lives and its possibilities has been found to have effects at not only a psychological level, but a cellular one [16-23]. However, unlike medication, fairy tales treatments have significantly differing effects patient to patient [5,24-28]. This reflects the need, according to Gnezdilov’s [1] approach, to construct highly individualized fairy tales for patients, tailored to their circumstances and needs. For Gnezdilov [1], there is no secret of how a fairy tale works: A famous line from the poem of the Russian poet Pushkin [29] illustrates his view well: “A fairy tale is a lie, but it is also a hint and a lesson” (translation by the authors). Hence, fairy tales work indirectly through activating imagination, opening a space for possibilities and affecting the concept of individual time. Armed with lessons gained via fairy tales, one can overcome many difficulties [4,30].

The concept of time has received a good deal of attention in the health care literature. When a patient encounters a serious illness, time becomes a matter of great importance. In healthy people, time is conceived as a natural flow where time perception is “always directed towards our future but simultaneously shaped by our present and past”. Gergel [31] argues that illness affects the time perception. When patients experience an episode of pain, time slows down or even stops [31]. There is a paradox here as the dying also perceive that time moves too fast and there is not enough of it, as it was observed by Gnezdilov [1]. Time and its limits as part of the mortal human existence, has economic as well as personal value [10]. For people with serious illnesses, time becomes a question of depth rather than length [10]. Ellingsen et al. [11] suggest that one’s ‘inner time’, that is time felt within the body, dominates experience when the prospect of death is present. One of their findings indicates that a forced focus on ‘clock’ time gave participants a disturbing feeling of falling behind in time and of being an outsider [10]. The authors conclude that the certainty of death experienced by their participants, revealed to them the meaning of time [10].

This study will contribute to the conversation around the use of fairy tales in care by exploring the experiences of those involved in delivering care by this method in relation to the notion of time. To do this, we draw on data generated by a focus group interview with Professor Gnezdilov (AG) [1] and his team members who use the method in the delivery of palliative care in Russia.

Participants and Data Collection

There were a total of six participants in the focus group study (AG plus five further team members). The five team members consisted of one medical doctor, one nurse/music therapist and three artists in residents (one singer, one guitar player/singer and one professional singer). The team was selected in relation to their extensive experience (over 10 years) working with the method. The focus group interview was facilitated by the primary author (EBH) in September 2016 in St. Petersburg, Russia, in a hospice space where Professor Gnezdilov [1]

works with patients in end of life situations. The purpose with the study was presented to all the participants before the interview started and all the questions from the interview guide were verbally clarified. The focus group took place as a conversation of participants, sitting around the table and lasted two hours. The following open-ended questions were asked:

1. How would you describe your work with the fairy tale method?
2. How do you work with the different steps involved in the fairy tale method?
3. In what ways may a fairy tale affect, in your opinion, a human being (with or without a sickness)?
4. How do you look upon the time perspective of a FT?
5. Which role does sculptures, music, songs, have in relation to the fairy tales?

The interpreter was sitting next to AG and with the help of a translator, exchanged the questions and answers. The team members were describing different elements from AG’s Fairy Tale method during the interview. The interview was recorded and transcribed ready for analysis.

A follow-up interview, lasting approximately thirty minutes, was conducted via telephone (on the 19th of May, 2017) between EBH and AG. This helped to clarify any potential misunderstandings of the interpretations from the recorded texts. The interview also served as a first test of the validity of the findings through communicating a summary of the initial findings and eliciting participant feedback on the reading of time as a theme in the texts.

Data Analysis

The data generated in the focus group was analyzed following the phenomenological-hermeneutic method inspired by the French philosopher Ricoeur [12]. This method has previously been used in different contexts in relation to health care [13-15].

The phenomenological-hermeneutic analyses take place at the following three different levels:

1. Naïve reading, where all the texts are read through and a summarized, capturing the researcher’s understanding of the texts regarding the research questions and regarding the researchers’ previous knowledge and experience.
2. Structure analysis, which involves a closer reading and analyse of the data where meaning units, sub themes and themes are assembled in a structural order.
3. The complete interpretation where all the different levels are incorporated together (Naïve reading and Structure analyses) which forms an overall interpretation of the data that corresponds to the research questions [11,14,16].

In this paper, we present a condensed synthesis of the different themes by using example quotations. This serves to exemplify how the themes discussed were derived from the focus group data.

Validity and Trustworthiness of the Data

The primary analysis of the texts (naïve reading and structure analyses) was made by the first author and thereafter peer-reviewed by the second author. The total interpretation of the data was generated by both the first and second author in relation to the literature and the

research questions. This combined reading of the data helps to increase the validity of the study.

The phenomenological-hermeneutic method is considered to be valid when the researchers are able to demonstrate a good knowledge of the research context and when the interpretation of the naïve reading and the structure analyses are made in accordance with the methodological guidelines. The generalization of the data during the total interpretation is made only insofar as the knowledge claims extend to the phenomena in question, which means that no generalizability is claimed beyond this specific context.

Another contributor to the validity of the research stems from the variations in the backgrounds of the two researchers, namely, differences in the researchers' academic disciplines and cultures. EBH is a researcher who works principally in the fields of culture and health; she works clinically with stress related disorders, such as exhaustion and pain; and comes from Sweden. NT is a researcher in marketing, with an academic background in communication; and who comes from Russia. The constellation of different disciplinary and cultural perspectives, in addition to differing knowledge of languages, allowed for the taking of different perspectives on the data. This resulted in multiple readings of the data and the production of a particularly rich interpretation.

Limitations

One limitation of the study is that the data was generated from only one focus group. Nevertheless, the specific group of people who took part was composed of long term experts in the FT method; they had in-depth knowledge of the method's principles and experience of using it over ten years.

Another limitation of the study is that the data texts have been interpreted from Russian to English language, and therefore there was a risk that some of the culturally-embedded nuances from participant accounts, and therefore participant experiences, may have been lost. This risk was mitigated by the fact that one of the researchers is native Russian speaker and was able to engage with the original Russian texts directly to pick up on any differences in translation.

Results

The Naïve reading:

- A fairy tale is understood as being a metaphor related to a specific moment.
- A hospice is not seen as a final destination – the fairy tale can change our time perspective with regards to the finality of time.
- The fairy tale changes our perception of time.
- The fairy tale can save us from the “yoke” of time.
- Situations can be seen from a different point of view with the help of fairy tale characters.
- A fairy tale can work as a guide, which helps each of us to better adapt to the “after-life”.
- Theories embedded in the fairy tales suggest that we do not die, but rather we prepare ourselves for the next step.
- The fairy tale has the capacity to help patients detach from their disease by starting to detach from their parents.
- By engaging with a fairy tale, you can regain self-control and create a perspective of infinity for your future.

- Through the fairy tale, you are helped to accept your disease and therefore become able to take next step.
- The quality of time is more important than its length.
- The response of the patient to the fairy tale activity can be measured by following eye movements, heart rate and breathing patterns.
- Music making, singing and sculpture-building is part of the Fairy Tale method and may deepen the embodied response, i.e., patient can start to express deep emotions more easily, and to cry, when there are other modalities involved.
- A fairy tale can make sorrow disappear from the heart – thereafter there is more space for happiness – it is therefore a transformative process.
- It is never dangerous to get in contact with your emotions during the fairy tale method.
- A fairy tale facilitates contact with the wisdom of earlier generations and, simultaneously, the time perspective changes and disappears.
- When listening to a fairy tale we fall into a sleep mode in which forgotten memories reappear and time disappears.
- Different sounds from musical instruments affect our perception of time in conjunction with the FT.
- It is important to find the right musical instruments that suit both the person's own body symptoms and the content of the fairy tale.
- When you embody the FT, you feel more safe.

As the next step of analysis, the data above was organised into three themes. These are presented below.

Theme 1: A multidirectional time continuum

The fairy tale function, as represented in the accounts of AG and his team, can be interpreted as a form of “time machine”. The fairy tale acts as a vehicle in which the patient is facilitated in travelling back and forth in time. The patient moves along a multidirectional time continuum. Perceiving time in accordance with a multidirectional axis allows a person to have, or regain, agency in relation to time.

Seen in the quotations below, the patients can change their perception of time, to begin to merge their experience of the fairy tale with the real world by drifting in and out of the FT, and to reformulate the notion of death. These changes in perspective alter time by constructing life-time as a never-ending continuum:

“We change our perception of time by means of the fairy tale; we become one with the fairy tale”. (P2)

“We can go in and out of the fairy tale and thus change our perception of time”. (P3)

“You do not die of your illness but by means of the fairy tale, you only enter another phase of time.” (P6)

“The fairy tale can bring you back in time.” (P4)

Thus, in the context of health care, we might see the FT as a tool that can be used to help patients to re-organise their experience of time; to travel in different directions depending on their needs and wishes. The fairy tale gives the patients access to a time machine.

It is also of note that the quotations indicate a differentiation between the ‘flow’ of time, from its properties as we might ordinarily think of it:

There is no future or past 'fairy tale time', only an existence on a time continuum, which is accessible through the FT. Time is either qualitative or quantitative – only a state of 'flow'. (P1)

The fairy tale can create a revocation of self-control, and thus strength to create infinity. (P3)

The flow of time may be interpreted as the non-existence of time: the fairy tale allows time to take on a quality that is related to a state in which time is endless. The fairy tale as a multidirectional time continuum also involves a possibility to revoke self-control and strengthen a capacity to create infinity; transform the mind into a new after life time continuum. These quotations below express part of the multidirectional possibilities of the fairy tale time.

Theme 2: Intensification of time

Within this second theme, the fairy tale is regarded as an intensive experience:

"Everything is about the metaphor at the very momentous moment." (P2)

"I get in touch with generations who have gone before - a kind of strong focus and it will be real." (P5)

"One decides to succumb to crying and then be happy." (P6)

The fairy tale is symbolic, lending it intensity of meaning. The FT is, moreover, a flexible object that can be adapted to suit the purpose and the meanings required by the patient through its modal intensity: By using different modalities such as musical instrumentation, the narrators voice, and songs. Through the addition or omission of these, the intensification of the patient's engagement with the fairy tale may be regulated. Further quotations from the data explain that this intensification process also relies on the expertise of the person facilitating the FT method:

"The environment and the narrator's professionalism are important for how trustful and real the fairy tale can be." (P3)

"The music and the voice of the narrator change the experience of the (FT) story." (P4)

From the analysis of these accounts generated by the team of FT experts, the experience of the fairy tale appears to become something one can reinforce or diminish, and the intensification of the time process used differs significantly depending on the specific needs of the patient.

Theme 3: Alertness to time

In a third theme, the fairy tale is regarded as something one can use to make oneself disappear in time. The interpreter of the fairy tale can regulate your alertness to time through the FT. This regulation affects the patient's awareness of time: it offers a distraction to the patient, taking their attention away from "reality".

So, the fairy tale opens a possibility to regulate not only the intensity of fairy tale time by using props and music (Theme 2), but also the patient's alertness to time in the real world. By engaging with the FT, the patient becomes less aware of 'real' time:

"You become more or less alert in relation to the FT, you become the FT." (P3)

"The FT can act like a piece of music (there) it will be a kind of distraction from their (patients) reality." (P4)

"FT can free us from the yoke of time." (P2)

"One focuses on the FT so intensively that it can make it so real; we do not die, we just take a new step." (P5)

"As the listeners enter the FT, everyone can decide how to contact previous generations, to become one with them." (P6)

Through directing the patient's sense of time to that of the fairy tale, which is often non-existent or infinite, the patient is released from painful experiences of the loss of real time. The patients enter into a transit in which they can regulate their awareness of and alertness to time.

The Complete Interpretation

In the final step of the analysis, all the texts are considered as a whole: we integrated the naïve reading, the research question, the structure analyses and additional notes on the researchers' pre-understanding and knowledge of the field. This step is called "the complete interpretation". This produces a higher-level interpretation of the data and is presented as follows:

The fairy tale as a multidirectional 'time machine' – mediation of hurriedness and awareness

When analysing how Professor Gnezdilov [1] relate the "fairy tale" work to the concept of time, we found three different but interrelated themes. First, the multidirectional time continuum, in which the fairy tale is seen to have the capacity to shift the patient in time; second, the possible intensification of the patient's perception of time (through the layering of the FT with other media such as music); and third, the alertness to time of the patient who interprets the FT. Considering these in concert, the potential to alter time could be described as a "time machine" tool, that can be mobilized to regulate time through experience of the fairy tale. As a communicative vessel, the "FT time machine" affects both the FT time itself and the time perception within the perceiver.

In the model presented in Figure 1, the interrelated function between the patient and the fairy tale is presented as a stick figure/human being on an x-axis where the fairy tale can expand and diminish in relation to the time-axis.

Discussion

The purpose with this study was to 1) describe how AG's team use their FT method 2) to examine the relationship between the method and the concept of time. We developed the notion of a 'time machine' to describe how the experience of the fairy tale holds promise for the patient in how it can alter the perception of time. Two concepts of time, borrowed from the Ancient Greeks, are useful in thinking about the time machine — Chronos and Kairos [23]. Chronos was a quantitative measure for the intervals of time; its progression and periodization. Kairos related to the qualitative nature of time, it indicated an event that can only happen "at that time". Kairos is therefore the interpretation of what happens in Chronos. This concept of time allows us not only to measure, for example the life span, but also to take into account the meaning of life. In relation to the findings of this study, there is an evidence that with the influence of FT, the perception of time changes from an emphasis on a unidirectional and linear concept of time (Chronos) to finding the meaning in events that

have happened, and to revisit and re-evaluate them (Kairos). Searching for the life meaning becomes especially acute during severe illness and the realization of the fleeting nature of time [23]. As seen in Ellingsen et al.'s [11] study on patients living with severe incurable diseases, time becomes a question of depth, not of length.

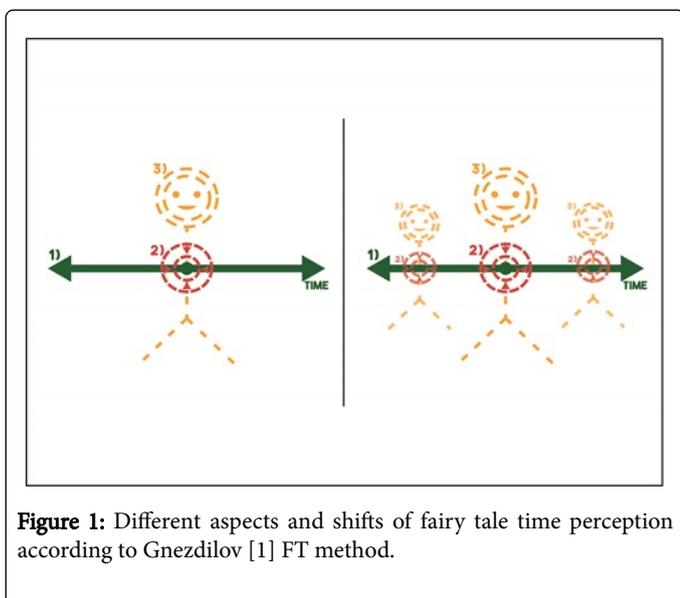


Figure 1: Different aspects and shifts of fairy tale time perception according to Gnezdilov [1] FT method.

The multidirectional time capacity, presented in the model of the FT, includes a mediation of perceived time. A calibration of awareness can be made through the fairy tale in relation to time.

- 1) Multidirectional time continuum. The FT function makes it possible to travel back and forth in time (green time axis).
- 2) Intensification of time. The intensification of the perception of the FT can be made through different props (yellow circles)
- 3) Alertness of time. The interpreter of the FT can regulate its perceived alertness (red stick figures).

We consider now how this fairy tale 'time machine' tool might also be used in our everyday lives. Stress is, in modern society, a common and deleterious experience for many [17,19,20]. Today, for the majority there is a necessity to attend to more chores that one is capable of fulfilling. This results in a lifestyle of extreme acceleration and ultimate hurriedness. Attempts to multitask and to 'time-crunch' result in time becoming a precious commodity [5]. Hyperculture [25] observes that increased speed of living puts pressure on contemporary people that is "strong enough to shatter the structural integrity of our personalities, of our human relationship and of our society itself". This stress makes individuals physically ill [24]. Work-related stress is thought to be one of the main causes of burnout, which affects not only those individuals and their families, but also health care personnel who provide palliative care [14,17-20]. Work-related stress is responsible for costly sick-leave for employers, especially in the health care sector [21].

The fairy tale method could be used as a mediator of the hurriedness (of time), leveraging its regulative capacity beyond its original audience: The fairy tale tool offers the potential for transforming the way in which we perceive time in our daily lives, serving as a form of 'buffer' against stress. On the societal level, the speed of living affects the fabric of culture, where "traditions become incomprehensible and history becomes irrelevant" [20,25]. Some valuable experiences require slowness; they develop from psychological

maturation and involve the building of meaningful relationships and "the search for answers to life's greatest problems and mysteries". The capacity to do this disappears in our fast-paced modern society [25]. Hyperculture [25] suggests that digital clocks replaced mechanical clocks and have become a symbol of our time. Because they are 'frameless', digital clocks do not offer a sense of the past, the present and the future as mechanical clocks do, the digital clock only displays the passing of time [5]. Digital clocks favour Chronos, the quantitative and linear measure of time. Kairos is brought into relief through immersion in the fairy tale; experience of life becomes more intense. The intensification of the experience may in part be explained using the multimodal theory [27,28]. When we combine different modalities at the same time we increase the perception of our emotional response compared when using only one modality at a time. This is frequently used in other therapeutically context to open/stimulate the emotional brain [29], i.e., when dancing with, instead of without, music. In the contemporary world where "there is an increasingly frenzied search for Kairos" and the fairy tale method may lend us some way to find it.

Conclusion

The study shows that the FT method relates to three different time perceptions 1) a multidirectional time continuum 2) an intensification of perception of time and 3) the alertness to time of the patient who interprets the FT. These three themes create a possible tool, a "time machine" tool, which can regulate both the experience of the speed with which time passes and awareness of the quality of time. This knowledge, borrowed from fairy tale traditions used in palliative care in Russia, offers opportunities for further evaluation, dissemination and implementation into new contexts. In particular, we might seek to mobilize them in relation to the problems we face in daily time with regards to increased hurriedness and stress.

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