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CARE FOR THE DYING IN THE LATE USSR (1970–80S)

Disclosure of the diagnosis is a structural element of modern hospice ideology: the patient must be aware of the diagnosis in order to manage their dying and allow care instead of treatment. Care in hospices makes the last period of one's life comfortable and maintains the habitual way of life of the dying person. Disclosure of diagnosis, awareness of death, and normalization of dying are thus three interrelated elements of modern hospice infrastructure. However, the case of the late USSR does not completely fit into this rule. On the one hand, there were no hospices in the Soviet Union because any formal disclosure of a diagnosis was banned. On the other hand, based on the study of archival and personal sources, I conclude that despite the concealment of the diagnosis, almost all dying people were aware of their impending death; in the absence of hospices, the dying received homecare; the patients also continued to lead their usual way of life. Hence, concealment of the diagnosis did not lead to unawareness of impending death and a lack of care infrastructure. To explain this paradox, I apply theoretical frameworks developed by Oleg Kharkhordin and Alexei Yurchak who argue that Soviet society had a binary structure consisting of a public ritual part and a private natural life. The nondisclosure of the diagnosis in the USSR was of a ritual form with a reversible function—hiding the diagnosis meant indeed disclosing it. This explains the structure of the Soviet model of care for the dying. The state did not officially deal with the dying and discharged them to their homes, providing them with some support. When the Soviet health care system sent a person home to die, it essentially segregated the private and the public, making it possible for care and dying to happen at home.

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Diagnosis disclosure is a structural element of western hospice ideology – a patient must be aware of the diagnosis and its consequences in order to be able to manage dying (Bass 1985). When aware of the diagnosis, a person does not waste time and resources on useless treatment, refuses long-term planning and tries to make the last months of life comfortable, maintaining his usual way of life or improving its quality as much as possible in his condition. Hospice care infrastructure assists the patient and ensures an acceptable level of physical and mental activity – its medical staff control pain and provide psychological counselling in order to reproduce home life in a hospice environment. Disclosure of diagnosis and awareness of death perform the function of deploying and using the hospice care infrastructure to normalise dying in modern western societies.

The modern western hospice ideology of care for the dying was shaped in a specific socio-historical context of (1) the secular concept of physical pain, which is associated with human rights and an approach to 'good dying' (Bourke 2014; Moscoso 2012); (2) professionalisation of nursing where medical staff are supposed to relieve the suffering of the dying rather than take religious care of their souls (Clark 2016; Stolberg 2017); (3) formation of the welfare state (Clark 2016); (4) general humanistic discourse with an emphasis on the patient's subjectivity/autonomy (Kaufman 2006); (5) the growth of new social movements, including the development of the institution of volunteering and private philanthropy, as well as the increase in feminist movements stating the importance of care practices (Timmermans 1994, McNamara et al. 1994). The entire system of care for the dying stands on three interrelated elements: the disclosure of diagnosis, awareness of death, and normalisation of dying which was formed in a special socio-historical context (Glaser, Strauss 1965, 1968; Field, Copp 1999; Seale et al. 1997; Seale 1998).

Compared to this, in Soviet medicine, there were no such practices as the disclosure of the diagnosis and the open discussion of the problem of dying which constitutes awareness of dying as open interactions where both the dying person and the caregiver knew that the person was dying (Mokhov 2021). In the absence of many elements of socio-historical context described above, hospice care infrastructure (in the form in which it arose in Western countries in the 1970–80s) did not appear in the USSR. However, while conducting interviews with people who looked after their relatives in the 1970–80s, as well as working with diaries and archival documents, I noticed that in Soviet society, despite the concealment of the diagnosis, almost all dying people knew about their extremely unfavourable prognosis. There were no hospices, but the dying received home care and support. Patients also continued to lead their usual way of life, trying to normalise their dying. This gave the impression that the USSR had its own model where disclosure or concealment of the diagnosis, and the normalization of death and awareness of dying worked differently from the west.

The purpose of this article is to show that as a result, this situation produced an alternative to hospice care infrastructure. The central questions are then: What was this model of socialist care for the dying? How did it work?

Concealment of The Diagnosis, Normalization of Death and The Drama of Pretence

The model linking diagnosis disclosure, normalisation of death and nursing practices was first conceptualised through 'Mindfulness of Death' by sociologists Barney Glaser and Anselm Strauss (1965). This work presented a detailed typology of communication between doctors, medical personnel, relatives and patients, as well as, most importantly, the product of this communication. This book was written in 1965 when most American doctors did not report terminal diagnosis. It was not until the mid-1970s that most physicians began to report such diagnosis (Novack et al. 1979). Among the reasons for this change were the transition to insurance model of medicine, the commercialisation of medical services, as well as public criticism coming from various grassroots social movements. Diagnosis disclosure has become one of the watersheds in the development of Western healthcare systems and heralded a turn towards patient-oriented medicine (Bardes 2012).

According to the Glaser and Strauss model, there are several basic communication strategies and death trajectories arising afterwards: (1) Concealment. The diagnosis is not disclosed and there is no awareness of death, which entails a rejection of nursing practices in favour of treatment; (2) Suspicion. The dying person suspects his diagnosis, which is concealed from him but is not sure about it. There is no awareness of death, dying is also difficult; (3) Pretence. Everyone knows about the diagnosis, but the parties pretend that the diagnosis is favourable. Despite a certain awareness of death and openness to nursing practices, an imitation of treatment remains, and a lot of resources are spent on maintaining the illusion of successful recovery; (4) Openness. Everyone knows about the diagnosis, you can see a high level of awareness of death, which facilitates nursing practices.

The strategy of pretence arouses interest in this typology. As I mentioned above, incurable diagnoses were carefully concealed in the USSR, but patient and relatives were well aware of what awaited them. In describing this strategy, Strauss and Glaser turn to Goffmanian dramatic sociology and deal with the situation of dying using the metaphor of theatre. According to them, performing the drama of pretence, all participants understand that the diagnosis is disappointing, but they continue to behave as if it is favourable, maintaining the illusion of a positive course of the disease. Communication of pretence means that the participants are not only silent about the diagnosis, but they go on performing a series of ritual actions, for example, they do therapeutic procedures that supposedly can cure the patient; the family is talking about future plans after recovery, which are not destined to come true, and so on. The applied result of this drama is that the normalisation of death does not occur (or occurs partly) and the provision of care practices is complicated. However, I cannot accept this strategy as an analytical framework for the Soviet case: how did the total concealment of the diagnosis work with the home care infrastructure?

Although Strauss and Glaser's model is based on interactionist logic, the reasons why people choose any of the strategies are in the context in which communication takes place. For Strauss and Glaser, this context is American clinical culture. Contextual reading becomes possible due to the Goffmanian reading of interactionism, which sits between the micro-optics of observed situations and the broad structures of explanations that can be given. Actually, Glaser and Strauss began to substantiate structuralism in Goffman's interactionism as early as 1972 (Glaser, Strauss 1964). Thus, their explanation of the formation of care system and how the key elements of the system work always lies in the context, or rather in the social structure. Taking this into account, the drama of pretence may work differently in the Soviet case considering the specifics of Soviet context.

In order to contextually explain the work of concealing a diagnosis, I turn to the works of Oleg Kharkhordin and Alexei Yurchak (Kharkhordin 2016; Yurchak 2006). These scholars explain the work of formalized practices in Soviet culture and the function of these practices. They note that many of the public practices were read by ordinary people in reverse (false as truth). The Soviet society had a dualistic structure, with an official part and a private part. These parts were literally in opposition to each other. Oleg Kharkhordin contends that a Soviet man was a 'dissimulating animal' and had a 'split mind' (Kharkhordin 2016). The researchers note that pretence served as one of the tools for preserving private life from total government interference (Yurchak 2014). Aleksei Yurchak argues that by the 1970s, the official discourse had completely been formalised, and public life had actually been reduced to purely ritual gestures, while the real social and cultural activity of the Soviet people was in a private context. The existence of pretence (as a tool for the segregation of everyday areas) created various parallel structures supported by the Soviet system itself since they made it possible to fill gaps, for example, in the shadow economy (Ledeneva 1998).

The purpose of this article is to outline the general principles of the structure of the Soviet model of caring for the dying people through the analysis of reconstructed communication around the dying, clarifying how it became possible that concealment of the diagnosis does not influence the normalisation of death and the care infrastructure. I assume that the Soviet health care system acted in a similar logic keeping the formalised protocol of concealing the diagnosis *de jure* but communicating it *de facto* – it rigidly separated the official medicine (with no dying and seriously ill patients) from the private life (at home, where patients moved after discharge).

Sources and Methods

A series of interviews with people who had experience in caring for dying people in the period 1972–1991 was used as the source base for the work. The choice of this period is explained by the following. First, the ideology of a good dying appeared in the West in the period of the 1970–80s; therefore, it is necessary

to compare the same epochs. Then, recruiting opportunities also impacted this decision: the events took place fifty years ago, so it was extremely difficult to find informed subjects for an interview. The informants were close relatives of a deceased person: their child, partner, sister or brother. Certainly, people's perspectives on the death of a relative differ depending on their family and social position. However, the purpose of the interview was to reveal general and structural elements of care practices.

The places where the events took place were located mainly in the central part of the RSFSR, the social status of families may be conditionally described as the Soviet middle class (management personnel, mental and cultural workers, highly skilled workers). The main cause of death was cancer. The number of interviews is 12, and the duration of each is from 1.5 to 2.5 hours. The interviews are anonymised according to the agreement with the informants. During the interview, they were asked about medical care, including nursing; peculiarities of communication in their families; about leisure.

In addition, I use archival documents, diaries and letters; data from secondary sources, including available official statistics (for example, mortality of cancer patients; growth dynamics of oncologic dispensaries, etc.) for the period from the late 1960 to 1980s, presented in the specialised medical literature. Moreover, as another source, I use popular scientific literature and art films, publicised in the USSR during the specified period. The main methods are narrative and critical source analysis.

Concealment of Diagnosis and Awareness of Death: Reverse Function and Ritual Work

Deontology was the ethical code developed in the USSR to treat cancer patients, and it forbade incurable cancer patients to be informed of their diagnosis (Peterson 1980). It was believed that concealment of the diagnosis is good for the patient, and in this case, he or she is determined to be cured and does not give in to despondency:

Despite the propaganda of curability, the word 'cancer' has a depressing effect. Anything that could have a negative effect on the patient must be excluded... A doctor was advised to prepare to play the role without weekends and intermissions in order to shield the patient from what he had to expect and, more importantly, what threatened him (Gershanovich, Paykin 1980: 62).

Unlike in other countries, such as the United States, where nondisclosure of a diagnosis was a personal choice of every doctor until the 1970s, concealment of a diagnosis in Soviet medicine was a system of binding prescribed rules and protocols. It was advised to mislead the patient to conceal his diagnosis, for example, by specifically drawing his attention to unimportant signs of the disease (colour of palms, size of nails, rashes, etc.), trying to distract him

from those that were important for disclosing the diagnosis. It was prescribed to indicate erroneous diagnoses and deliberately prescribe harmless and use-less medications so that the patient did not lose hope for a cure: 'It is necessary to occasionally change medications, options for their prescriptions, ways of taking them. The doctor cannot tell the patient that all the remedies have been exhausted and there is nothing more to add' (Glebova, Virin 1982: 64–66). Diagnosis concealment was an institutional rule of Soviet health care.

However, it should be borne in mind that the concealment of the diagnosis occurred against the background of high mortality from cancer and the widespread prevalence of the disease. The fact is that patients with incurable stage IV cancer consistently accounted for 25% of all initially detected cases. Also, 15–20% of the patients with stage III, which inevitably turned into stage IV in the first two years of the disease, could be added to that number. The percentage of neglected cases continued to be very high until the late 1980s. Mortality from the disease detected in the first year was about 35% (Zaridze, Basaeva 1990; Napalkov et al. 1981). In terms of numbers, it meant that about 40–45 thousand people were diagnosed annually with an incurable form of cancer with an expected death in the coming year.

These numbers show that Soviet citizens were most likely familiar with the practice of concealing a diagnosis and it was part of their own close experience: relatives, acquaintances, colleagues and so on had it (Mokhov 2020). Every year, several hundred thousand people faced incurability and death from cancer in their immediate surroundings. They are reflected even in Soviet cinema, where they are easily recognised by the audience. For example, *The Time of Her Sons* by Viktor Turov (1974) shows a scientist-oncologist named Ivan Gulyaev who does not tell his brother about his terrible diagnosis. *When September Comes* by Edmon Keosayan (1976) also depicts a lieutenant colonel who shields his front-line friend from the diagnosis. The main character, Levon Poghosyan, flies back to Armenia and he doesn't know he will never see his family and friends again.

I argue that the widespread practice of concealing the diagnosis led to the situation where most Soviet citizens were aware that if they ended up terminal cancer, then the diagnosis would most likely be hidden from them. Moreover, many knew exactly how that would happen due to experience of such hidden practices. Everyone in the family, as a rule, knew about the diagnosis and the unfavourable development of the disease, that is, imminent death. Hence, the diagnosis was concealed rather formally:

When it became clear that my grandfather had cancer, and he was already in advanced form, well, it was the doctor who told my father about it. Then my father told my mother – they told me this later when I grew up and we used to remember that time. Grandfather, of course, was immediately discharged home and he understood everything himself. There may have been some intimate conversations between him and my father, but I don't think so. The situation was obvious to everyone (Woman, 63 years).

According to Glaser and Strauss, concealment of the diagnosis leads to four possible strategies. If we try to apply the Soviet case to this typology, then we can see that the failure to conceal the diagnosis does not lead to imitation of the situation, as if the diagnosis were actually favourable. On the contrary, everyone understood the consequences (of the disease prognosis) and acted as if the truth had been told. This happened because it was not the diagnosis that was imitated, but the concealment procedure itself. The concealment was carried out according to formal requirements. However, the Soviet people knew that 'truth is a lie' and if a favourable diagnosis and concealment of information were formally portrayed, it means that the diagnosis was bad.

As a result, the concealment acquires a reverse function – if we conceal something, it means we inform you. Taking this into account, the 'drama of pretence' in the Soviet case can be theorised as a ritualised pretence which concerns the practice of concealing the diagnosis rather than its consequences. It was some kind of a legitimate form of communication, but it did not have a straightforward function. The context of Soviet culture explains why hiding the diagnosis becomes a kind of ritual with an inverse function because such formal adherence to practices was widespread in many areas of everyday life.

The Normalisation of Dying: Everyday Life, Work and Relationships with the Family

The place where Glaser and Strauss believe the drama of pretence is played out, turns out to be empty in the Soviet case: the patient is discharged home, and does not continue to be treated in a hospital, as it takes place in the American medical system. Discharging home was one of the parts of the ritual-of-concealing-the-diagnosis reversal function, i.e. if you were discharged home, then it did not mean you were on the mend.

Moving a patient home from the hospital provided much more opportunities for normalising death, which could not be provided by official medical institutions. Relatives and dying people did not change the home environment to suit the person's needs but tried to preserve the usual order of things as much as possible. Considering it as the revealed diagnosis, this can be comprehended not as a theatrical game of normality, but as a completely conscious step, which Glaser and Strauss describe in the fourth strategy for complete openness. In other words, concealment in the USSR was complete openness in the USA.

According to the analysed sources, the dying person continued to go to work, he or she often insisted on his ability to work and continue his activities. In most cases, for his sake, the working day was shortened, he or she took sick leave and short-term leaves, but the very possibility of continuing his work activity was a very important element of everyday life¹:

¹ As a rule, a person received a disability and the right not to work when diagnosed with at least stage II cancer.

My grandfather worked until the very last day of his life. He worked in supply, as a head of something there. Well, he went to work regularly, although he used to leave work earlier, took time off when he needed to see a doctor, or felt bad. He stayed at home only in the last three weeks, when he had already gone to bed and it was clear that he would soon pass away... I think it was very important for him to realise and feel that he was still needed in his place, that they can't cope without him. It made him feel like life was going on (Woman, 48 years).

This should not come as a surprise. The subject of the Soviet person was represented through labour: materialist Marxist philosophy considered vigorous activity as the only way of forming a personality. This differs from what Glaser and Strauss describe relying mostly on a pragmatic understanding of the subject, i.e. the person who makes a choice and participates in consumption. Sarah Kaufman (2006) wrote much later about how a pragmatic approach forms the hospice ideology, emphasising that hospice allows maintaining the illusion of consumption, i.e. the subject can choose to consume. From this point of view, it seems quite logical that the Soviets caring for the dying person intuitively normalised dying by looking for similar opportunities to remain a human who participates in labour relations instead of consumerism.

We can see a similar approach to leisure. The sick continued to attend their favourite clubs and classes to the best of their ability, take walks and planned trips, including tourist ones:

We had a tradition to go to the sea, to the Crimea every year. That spring, when the mother's health worsened greatly, we decided not to postpone the trip and go on vacation as a family again. I think it was important for all of us to spend time together, as we used to. We prepared the car, simplified the route – we made more stops – and set off. Mother endured the trip and rested very heroically. She didn't complain, though she slept a lot and got tired quickly (Woman, 51 years).

The normalisation of dying and serious illness manifested itself in home life and household management. As evidenced by the collected materials, illness and a disappointing diagnosis, of course, made changes in the daily routine, but they did not look like an 'emergency.' All changes in home life fit seamlessly into the interior:

Nothing changed in our home. We had our own apartment, a separate one, but there were no major changes even in it. Yes, there was always a stool with medicines next to the bed. My grandfather's friend and my father made handrails in the bathroom to make it easier to wash. But there were no serious changes. Even our food didn't change. Life was going on its usual way (Man, 64 years).

The main changes, which were highlighted in many interviews I took, concerned family relationships. In this focus, dying at home is one of the most important, albeit not so ideologically meaningful, achievements of the Soviet system because many families got the opportunity of constant contact with their dying relatives:

It seems to me that the main change concerns relationships within the family. They became warmer, more caring. It may sound strange, but I remember the time when my father was dying as one of the best, albeit tragic moments in my life. We spent a lot of time together, he told me something, and gave me some advice. I was 13, I already understood everything. Mother and father began to communicate more respectfully with each other, although they used to swear constantly (Man, 53 years).

At the same time, patients express serious concerns in their personal diaries regarding the potential discomfort that they can bring to their families such as smells, limited movement, pain and the need for treatment. However, those experiences remain inside, not going beyond the pages of their diaries. In general, I can say that the life of a sick person's family was an attempt to reproduce a normal life, which they had had 'before the disease.'

Care Infrastructure: Pain Relief, Visiting Nurses and Privacy

Despite the widespread belief that there was no specialised care for seriously ill patients in the USSR, the Soviet health care system still had its own care infrastructure. As it has already become clear, it was not based on inpatient hospices, but on home support with the help of local activists and visiting nurses. This nursing infrastructure included several important institutions: (1) the Red Cross patronage nursing service and (2) specialised classes for teaching relatives in home care (CGANTD; GARF F. 8009 O. 55 D.144, D.149). Also, there was a well-established publication of popular literature on the topic of care: according to the most conservative estimates, over 5 million copies of various methodological literature devoted to caring for seriously ill patients at home came out in 1965–1991. This infrastructure was not aimed exclusively at seriously ill people, let alone dying people, but they also fell into the field of social support.

According to my interviews and archival sources, this infrastructure actually worked. I cannot say that visiting nurses provided a really significant help or their presence was impactful, but most families note that nurses visited them, asked about the patient's condition, and provided care. However, most of the care work was done by relatives:

Everything was done by my aunt. She took some courses, I don't remember exactly which ones, but she was well aware of what to do, and how to wash. She knew how to give injections, too. The nurses came, but rarely – there was no particular need for them. The doctor called occasionally and asked about the condition. But after we were discharged and the further treatment turned out to be useless, everything fell on our shoulders. It was quite clear and logical. That kind of thing. The nurses could come to see if there were any complaints, but we did all the care ourselves (Woman, 63 years).

Although it is generally accepted that there were serious problems with pain relief in the USSR, my informants do not mention pain relief as a particular

problem. Anaesthesia could be obtained, including medicine containing narcotic substances – for example, 'promedol.' The visiting nurses came to give injections. However, it continued to be shameful to experience pain:

My father had been skiing his whole life. So when he started having pains, he went skiing in the park. That was the way he was distracted and probably did it so that we would not see his suffering. I will remember for the rest of my life the day when he left at 4 a.m. with skis. He was tossing and turning all night, refused pills, and at 4 a.m. he took his skis and went to the park (Woman, 48 years).

Pain was avoided, hidden and ashamed of. Enduring pain was considered a necessary quality of experiencing the disease, and it might have been a reason why the very need for pain relief was reduced in many patients.

Conclusions

Strauss and Glaser's contextual model assumes that it is impossible to realise death and deploy a hospice care infrastructure without an open communication of the diagnosis. At the same time, they considered the problem of communicating the diagnosis in a very straightforward manner, i.e. only an open communication about it was deemed possible, and concealing the diagnosis was interpreted, at best, as drama of pretence. This is the main weakness of their typology if we want to apply it to other cases: Glaser and Strauss did not take into account that concealment (lying, hiding, etc.) may have different cultural grounds and outcomes, i.e. it may occur according to different rules and lead to different consequences. For example, what happens when pretence is one of the main communication strategies? A person is trained to pretend and knows how to recognise a lie – that is the way it is in the Soviet case (Kharkhordin 2016; Yurchak 2006). Therefore, the nondisclosure of the diagnosis in the USSR was of a ritual form with a reversible function – hiding the diagnosis meant indeed disclosing it.

Such conditions made it possible to deploy the care infrastructure on the same mechanism of pretence. The state did not officially deal with the dying and discharged them home, providing them at the same time with some kind of support, for example, medical visiting nurses, pain relief, and literature. This logic was embedded into a binary Soviet structure consisting of a public ritual part and a private one, a sort of natural life. As Oleg Kharkhordin and Alexei Yurchak show the Soviet society had a dualistic structure, with an official part and a private part and these parts were literally in opposition to each other. When the Soviet healthcare system sent a person home to die, it essentially segregated the private and the public, making it possible for care and dying to happen at home and created all of the care infrastructure based on home support.

Materials from interviews and other sources show how the everyday life of a Soviet family with a dying person worked to reproduce 'normality.' It was the preservation of the usual way of life rather than creation of a special space

of illusion (hospice). Life in the families with dying people practically did not change: the patient tried to go to work as long as possible, did the same leisure and sports as much as he could, the families went on vacation, organised family parties, and communicated with relatives and friends. Everyone knew the diagnosis, but they did not discuss it, reproducing a familiar illusion of life.

Thus, I can conclude that the Soviet care model was structurally different but did not differ in function: reproduction of the illusion of a normal life, dying as part of the life cycle, which did not require a 'state of emergency,' remained. While going through all the stages of formation and development of care model, this model duplicated the dualistic structure of the social life of the Soviet person, where the private was separated from the public (home care/hospital treatment) and followed the ritual logic of the protocols without fulfilling their intended purpose.

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