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ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/cmrt20>

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Sergei Mokhov

To cite this article: Sergei Mokhov (2021) Care for the dying in contemporary Russia: the hospice movement in a low-income context, *Mortality*, 26:2, 202-215, DOI: [10.1080/13576275.2021.1909226](https://doi.org/10.1080/13576275.2021.1909226)

To link to this article: <https://doi.org/10.1080/13576275.2021.1909226>



Published online: 10 Jun 2021.



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Care for the dying in contemporary Russia: the hospice movement in a low-income context

Sergei Mokhov 

Institute of Ethnology and Anthropology, Russian Academy of Science, Moscow, Russia

ABSTRACT

This paper offers a brief social history of the hospice movement in Russia. The author explains why the hospice movement has become so relevant over the last five years in modern Russia; who the people are who lead this movement; how their ideas collide with 'reality'; and what consequences of this collision can already be observed. The author presents the Russian hospice movement as a dynamic social process which arises in the particular context of the political protests of 2011–2012. The paper is based on the first results of ethnographic research conducted in several hospices in Siberia, as well as on data from in-depth interviews with hospice movement activists and archival materials. The author argues that the hospice movements in contemporary Russia serve a social function as grassroots mediation for social and economic care between local bureaucracy and patients.

KEYWORDS

Palliative care in Russia; hospice movement; social movements; social policy; death and dying in Russia

Introduction

Over the past 5 years, the efforts of activists and non-government organisations have brought the issue of hospice and palliative care to the attention of the entire Russian society. In March 2019, following these efforts, the first federal law on palliative care in Russian history was passed (№18-Federal Law). Straight after the law was signed by the Russian president, the leader of 'Vera' Hospice Charity Fund (organisation assisting local hospices) and the former head of the largest Russian hospice, Nyuta Federmesser, went on a working trip to 25 Russian regions. She planned to make a detailed report of these regions and to register their main problems relating to hospice work. The purpose of this mapping was practical. Nyuta Federmesser was to take on the main role in promoting the new government project 'Region of care' providing an active expansion of the Moscow hospice model to these 25 Russian regions.

Nyuta Federmesser began to publish detailed reports of this trip on her Facebook page. This working tour shocked her severely. She was shocked by extreme poverty and low standards of living in the Russian regions which inevitably affected caring practices. For example, she found out that theft of products and forgery of statistics was commonplace, and hospices in the regions lacked the necessary hygiene products. She commented in one report that: 'in many departments that I visited a bathing day happens only

once a week' (Feddermesser, 2019). She was struck by the everyday life of patients in hospices – some patients were tied to beds and did not go out for extended periods. Moreover, basic palliative care ideas of 'good death', 'dignity' and 'patient autonomy' were not understood by the medical staff: 'There are beds in hospices. People are lying on them. But it is not *care*'. (Feddermesser, 2019).

Feddermesser's posts have provoked serious discussions both in the professional community and among ordinary readers. Some people were genuinely surprised by her reaction, asking whether she indeed was not aware of how ordinary people lived and doubted the success of the programme 'Region of care'. Others blamed medical staff, patients, and local hospice activists. Nyuta Feddermesser concluded: 'We will teach them everything' (Feddermesser, 2019).

This story draws our attention to the 'reality' social care concepts and provision at local and national scales: misunderstandings between different groups of hospice activists; lack of resources; the difference in culture and values. How does the conflict between ideas and reality influence the system of care in contemporary Russia?

Theoretical framework: hospice movement from a local case to a big institution

First, I propose the following understanding of the hospice movement. Hospice is a place aimed at providing a body of social services and care practices for dying patients, mostly based on non-profit work including volunteer activity (Else, 1998; Graham & Clark, 2008; Greer, 1986; Siebold, 1992). The modern ideology of care for the dying was shaped in a specific socio-historical context of: (1) a secular concept of physical pain, which is associated with human rights and an approach to 'good dying' (Bourke, 2014; Khan, 2017; Moscoso, 2012; Rey, 1993); (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; Fissell, 2008; Lewis, 2006; Stolberg, 2017); (3) formation of the welfare state (Clark, 2016; Dunn & Milch, 2001); (4) general humanistic discourse with an emphasis on the patient's subjectivity/autonomy (Kaufman, 2006); (5) 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 (Graham & Clark, 2008; Pritzker, 2018; Rosenberg, 2011). Overall, we may conceptualise the development of hospices as a social and grassroots movement based on the ideology of 'good dying' which is based on modern humanistic discourse (Doka, 2003; Siebold, 1992). The development of hospices as a concept emerged in European culture in the middle of 19th century was given substance in the late 1960s and has been growing rapidly in the last 30 years (Lewis, 2006; Saunders, 2001). At the end of the 20th century, the hospice movement moved beyond the borders of the Global North and started to be imported to the Global South through the activities of the World Health Organisation, volunteers and local activists (Rosenberg, 2011; Stolberg, 2017). The hospice movement can be regarded as an imported product of 'Western culture'.

Given these structural features of the hospice movement as a set of ideas and practices, let's take a look at the Russian case, using the theoretical framework of historical sociology. Social movements and their consequences are a classic object of

research in cultural and historical sociology (Buechler, 1995; Sewell, 1996; Somers, 2008). One of the key goals of this kind of research is to explain the influence of social movements on social and political structures (Diani & McAdam, 2003). We may view the development of a national care model as a dynamic social process that takes place in a particular social context limited by certain institutional and cultural conditions. The main aim of such research is to restore the social and cultural context of the emergence and development of social movements. Informed by this theoretical framework this article aims to: 1) briefly identify the specific path for the formation of care for the dying in Russia and to trace its structure and institutional and social context; 2) address why the demand for the care for the dying in modern Russia has become such a focus of attention over the last few years; 3) identify how ideas developed by Russian activists in the hospice movement collide with 'reality' and what consequences of this collision can already be observed in contemporary Russia.

Methods and data

To answer these questions, I will draw on data collected during fieldwork, through interviews and archival research. In the course of the 6 months (2018–2019), I volunteered and took observations in several hospices in Siberia. I conducted 22 in-depth interviews with experts working in the healthcare system, hospice workers, volunteers in different Russian regions (Saint Petersburg, Moscow, Kazan, Ekaterinburg). I researched archival material from the State Archive of the Russian Federation (GARF), State Archive of Moscow Region (GAMO) and the Central State Archive of Moscow (TsGA Moscow).

Care for the dying in Russia: from early developments to the Soviet failures

By the end of the 19th century, a well-developed infrastructure of private philanthropy had formed in the Russian Empire. There were about a thousand different poorhouses and more than 19 thousand various charitable organisations in the Empire. By the beginning of the 20th century, there were six charitable organisations for every 100,000 people in the European part of Russia (Lindenmeyr, 1996). Such institutions provided almost 2.5 million people with social support including necessary care associated with serious illnesses or directly with dying (Sbornik, 1899). These organisations obviously did not look like modern hospices, but they were quite similar to the early hospices of that time in Europe (Lewis, 2006; Stolberg, 2017).

We know that care was practised on a professional level at that time. For example, Sisters of Mercy (*sestry miloserdiia*) – as nurses were called in Russia until 1926 – were paid for their work. They were not nuns like their predecessors, centuries earlier, and had to complete compulsory medical and body care trainings (Mirkovich, 1910; Simenjuto, 1910). The sisters could be hired to care for seriously ill patients in their homes. As diaries from that time show, this practice was widespread (Kazem-Bek, 1898). Professionalisation of care services started at the same time as the British nursing movement i.e. during the Crimean War (Sorokina, 1994). It is important to emphasise here that the Russian Sisters of Mercy were not trailing behind their European colleagues (DenBeste, 2017).

There were also basic values of the modern ideology of care for the dying. *The Death of Ivan Ilyich* (1886) by Leo Tolstoy describing the suffering of the eponymous dying

landowner, provoked extensive discussion in Russia. The topic of a good death, including the issue of pain, was an active point of consideration for Russian intellectuals during this time (Mogilner, 1994). Morphine was used for anaesthesia, including in small cities at the end of the 19th and the beginning of the 20th century. For example, famous Russian novelist Mikhail Bulgakov wrote his autobiographical story 'Morphine' based on memories of his work in a district hospital in the 1910s. Moreover, pharmacies at that time sold various drugs based on ether and morphine (Manyshev & Manysheva, 2019).

However, it is fair to admit that there were some major differences between Russian and European care systems. For example, the level of private philanthropy did not reach the European one and was 2–3 times lower per capita in terms of expenditures than, for example, in Berlin or London (Lindenmeyr, 1993, 1996). The biggest part of the population in Russia of that time was formed by peasants living in small villages; urbanisation was very weak (Shanin, 1972). The institution of secular charity did not reach Russian peasants at that time and mutual aid was already ingrained within traditional peasant culture. The level of political freedom was also much lower than in Europe.

Overall, we can assert that institutional and ideological conditions for possible future palliative care and hospice movement were in place in the Russian Empire. In fact, the first secular hospice (constituting a part of an oncology clinic) was opened in Moscow in 1903 by professor L. Levshin. This hospice was modern and fully equipped: it had 65 beds in single and double rooms.

These undertakings, however, were stopped at the start of the Great October Revolution. One of the first decrees (*signed on 20 January 1918*) of the new Soviet government – 'The Separation of Church and State' (*Dekrét ob otdelénii cérkvi ot gosudárstva i shkóly ot cérkvi*) – restricted the activity of the Orthodox Church. Along with monasteries and churches, charity organisations and poorhouses began to be nationalised and were transferred under the management of the local Social Security Commissariats (*Komissariaty social'nogo obespechenija*). Most of the Sisters of Mercy organisations came under the supervision of the Soviet Red Cross (*CentroKrest*) (Vysotskih, 2014). Levshin's hospice was transformed into an oncology institute. Nationalisation negatively affected the activities of these institutions. Revolutionary decrees and civil war led to the prohibition of private capital and its outflow abroad, to the plunder of property and looting, as well as to massive outflow of qualified professional staff (Kozlovceva, 2004).

However, as I noted above, the hospice movement received its actualisation in the late 1960s, so in what follows I talk about late Soviet society (1960–1980s). I have discussed what care for the dying, as a set of ideas and practices, is. I will examine how these ideas and practices were fundamentally different in late Soviet society.

Soviet ideologists declared a fundamentally new value approach to solving social problems, to human nature, and to the political foundations of social care. Firstly, Rosenberg argues that the ideology of dying is constructed on neoliberalism, individualism and market mentality in Western culture (Rosenberg, 2011). Sociologist Roi Livne links the rise of the hospice model with an ideology of consumption where life without consuming (life with suffering) is not considered a good life (Livne, 2019). This, in turn, becomes one of the foundations of the ideology underpinning Western care for the dying,

with its emphasis on the patient's autonomy noted above. The concept of care for the dying is a logical continuation of the neoliberal ideology of the consumer society that provides a seriously ill patient with the opportunity to consume thereby reproducing a 'life as consumption' model: hospices introduce a varied menu, various leisure activities, medical services and so on (Kaufman, 2006). From this perspective, Soviet society as imagined by its new ideology makers was fundamentally different, enforcing the primacy of the collective over the individual (Field, 2006; Kharkhordin, 1999; Yurchak, 2006). The public collectivism discourse prevented the problem of care for the dying from receiving attention in Soviet society. Personal needs (including personalised care based on consumption) were not important in contrast to the needs of the Communist Party and all Soviet society.

Secondly, it is important to note that the concept of 'humanity' in Soviet ideology was expressed through fundamentally different *subjectivity* in contrast to the Western world during the 1960s, using the term of labour rather than consumption. A person was considered to be an ideal Soviet citizen only if he or she could work and be useful for society (*kollektiv*). For instance, a patient's medical history (Adult Initial History Assessment, Medical History Questionnaire) was filled in by describing a patient's '*work path*' but did not include information about family or characteristics of the patient's daily life (McCagg & Siegelbaum, 1989). To enforce the rhetoric of *human subjectivity through labour*, the Soviet state sought to engage people with disabilities in relations of production. For this purpose, workshops were created, standards and guidelines with a list of professions that people with certain health problems could master were developed. People with disabilities who could not be included in labour relations were removed from public space (Phillips, 2009). A dying patient, incapable of production, and requiring only constant care, did not fit into this view of the world.

The Soviet system of core values comprised other important items. In 1920 a bill of the People's Commissariat of Health of the RSFSR No. 1026 appeared, and according to it, Sisters of Mercy had to be called simply 'sisters' and the word 'mercy' was removed from the profession's name (Konohova, 2012). This happened because the concept of charity was considered as bourgeois and thus not allowed in Soviet society. On the one hand, under communism, there would be no social problems as the future would bring complete social equality and so charity was unnecessary. On the other hand, individual financial assistance was considered an act of domination giving rise to social inequality. *The Soviet Dictionary of Foreign Words* (1954) explains: 'Private charity is one of the means of disguising the exploitative nature of the bourgeoisie'. For the same reason, no social movements were possible in Soviet society. Emerging initiatives comprised only programmes of volunteers organised by the state. As a rule, volunteering included the implementation of major projects: Union construction projects such as national building projects (Baikal–Amur Mainline), donation actions, and patriotic work (Boobbyer, 2005). In the Soviet view of humanity and the human body, there was no place for a personified concept of 'pain as a problem'. The suffering was valued as evidence of heroic sacrifice for the collective, and complaints about physical problems were perceived as shameful (Khaidarova, 2011). The problem of pain first appeared in specialised medical literature only in 1979, after the 3rd oncology congress (*III Vsesojuznyj s'ezd onkologov v Tashkente*), but remained a rare concept for years.

To sum up, it is easy to see that practices of care for dying people completely disappeared in the first years of the Soviet state coming to power. In subsequent years, Soviet society did not provide specialised assistance to the dying, such as cancer patients, despite the existence of small units in city hospitals, as well as local patronage services (*onkologicheskaja patronazhnaja sestra*). Until the collapse of the USSR, there had not been any palliative care nor hospice movement in the Soviet Union.

Care for the dying in contemporary Russia

Perestroika, the political movement for reformation of the Communist Party of the Soviet Union, brought serious changes. The principles of democracy, market relations, and liberal ideology were proclaimed. From the 1980s onward, the Orthodox Church returned to public life, and charity organisations began to reopen. In 1990, the first hospice in modern Russian history opened in St. Petersburg (de jure it was still the USSR). Over the next 20 years, about 10 private hospices and volunteer initiatives appeared in Russia. Mainly, their appearance was associated with the activities of Orthodox church and the initiative of Western charities. For example, the Catholic organisation Caritas initiated the opening of the first hospices in Siberia (Omsk), while it was due to the work of the British hospice activist Viktor Zorze that the first hospices were opened in St. Petersburg and Moscow. It is important to note that these were private, isolated initiatives happening on a relatively small scale (Wright & Clark, 2004). However, since 2011, palliative care has become central to public discussions about health care. Over several years, this movement grew from several local non-profit hospices to a public movement encompassing the whole country. From 2011 to 2018 the number of hospices rose to 90, the majority owned by the state, and receiving support from volunteers and small charities. What happened to fuel this rise of the hospice movement, however?

In 2011–2012 Russia witnessed the largest wave of mass political protests in its recent history. Several hundred thousand protesters gathered in different cities across Russia. The declared reason for protests was alleged fraud in the elections to the State Duma. For the next few years after the protests, former activists were subjected to serious political persecutions. Additional restrictive laws were passed. As a result, some of the activists emigrated, others were disappointed in the results of street protests. The latter group ended up forming a community that took up grassroots initiatives as one of the forms of less radical political activity. For many activists, charity projects became an alternative form of political expression (Bikbov, 2012; Magun, 2014). For example, the biggest Russian charity fund, ‘Need Help’ (*Nuzna Pomosh*), that raises more than 100 million rubles every year was established by the former political activist Mitya Aleshkovskiy in 2012.

At the same time, many activists joined the hospice movement. This happened not only in Moscow and St. Petersburg but also in other major cities where protests had taken place. Those activists began to take part not only in existing social organisations but often in newly created ones. In interviews, activists recognised that the hospice movement ideology was very familiar for them, for example, for the following reasons:

I came to the hospice movement around 2013. I was an activist during the Moscow protests, and after they finished, I wanted to do something useful. Then I met many people, and we

became friends. We wanted to change Russia. We asked ourselves – what can we do next? Taking care for dying people is very human, our society needs it.

The hospice movement has thus become an unconventional form of political protest. My informant continues: 'Charity is a good way to inform the public about the importance of human dignity. We understood that we need to start from this point and convey our point of view to ordinary people'. In conditions where it is forbidden to be involved in public politics, activists talk about leaving the dying. While it is forbidden to criticise the Russian authorities for authoritarianism and violation of human rights, former street activists make the choice to talk about care for the dying, thus veiling their political statement. Therefore, the hospice movement, as a set of ideas and practices, based on humanism and individualism has become a convenient form of criticism of Russia's social policy for former street activists. Hospice movement in contemporary Russia performs the function of criticism and control over political decisions taken in healthcare.

However, the activists found themselves working in very different conditions: the difference between Moscow and regions was striking. The Moscow model inherited the infrastructure in the form of the first hospice created by British activist Viktor Zorze, as well as significant financial support from Moscow city authorities. It took Moscow activists several years to attract well-known actors and journalists to their side and launch several successful crowdfunding campaigns. At the same time, activists in other Russian regions, while having practically no resources, began to adapt their volunteer activities to regional low-income contexts. It is an aspect outlined by one of my respondents:

We had an empty field before us. Everyone knew about dying children and many wanted to help them, but no one knew anything about dying among the grown-ups. However, the main thing here is that no one understood why they should help at all. People said: 'Why should we help them? They will die anyway'.

Regional hospices are mainly state institutions that are also a part of the bureaucratic regional healthcare system, so activists try to adapt their ideas to this context. Low income and underdeveloped private philanthropy encourage them to work in this environment, but how is this work performed?

When ideas collide with reality: the case of a Siberian hospice

I present below my primary observations based on fieldwork in several hospice departments in Siberia. I explain the main results of the first intervention of hospice activists in Russia, in reality.

I start with the question: how did activists make the problem of dying so popular? Why and how did the state answer to this problematisation? The interviews I conducted showed that hospice activists, using general humanising principles, demonstrated the scale of this problem that was potentially dangerous for the entire Russian political system: a lot of people do not receive care from the state, and this can affect loyalty. Activists sent the message to the regional authorities that a large number of people die each year who are not important to the government, but their relatives are important because they are your electorate. My informant said the following:

Our main task is to show people that they are dying in terrible conditions and everything here is connected: how they lived and how they eventually die. Of course, to some extent, we want to save the lives of people. We want them to see the reality clearly. The context of death is very appropriate here – this is the crucial moment when a person is ready to critically evaluate his or her life.

This attitude works as a convenient model for the modern authoritarian Russian state: grassroots initiatives in social policy are better than street demands for a change of government. Responding to the hospice community's demands, they eliminate street protests and, in fact, turn former activists into controllable providers of social services. My informant among bureaucrats confirms this: 'We respond to public issues. Dying was such an invisible problem before, while now volunteers have begun to talk about its importance. We respond – it is more constructive and effective than political street protests'. The state has formed practices of control for activists, subordinating them to unified financing. For example, in recent years, every activity involving foreign funds has been banned (FZ №121 2014 '*O nekommercheskih organizacijah*'). Until 2014, any NGO could receive various sources of funding (including foreign ones), but since 2014 it could not do it anymore. The unified governmental fund for allocation of grants – Presidential Grants Fund – has been created for all Russian NGOs. All initiatives that seek to receive some kind of funding for their activities are controlled by the state.

This situation has led to the need for collaboration with the state and eventually caused public discussion. Activists debated, quite heatedly, the question of acceptable levels of cooperation with the authorities. Radical activists believe that such cooperation is unacceptable even in charity projects. However, most activists tend to justify it, arguing that this is the only way to influence the situation under repressive conditions (Clément & Zhelnina, 2020). They appeal to the following argument: we cannot change the policy, but we can solve local problems. One of my informants concluded:

We realised that street protests will not lead to anything, at least not right now. So we decided to focus on useful things, for example, care for the dying. In general, it didn't matter to us exactly whom we would help. However, hospice ideology is very convenient. It helps to show how deep the crisis that our society finds itself in is.

For hospice activists, voluntary work is an alternative to their political activity and a programme for the humanisation of Russian society. For the state, it is a kind of a state control of activists. Oleg Zhuravlev argues that it's an instrument for channelling activists from street protests into controlled social projects (see also Zhuravlev, 2014; Zhuravlev et al., 2020).

That next question is what kind of care practices do they perform? As I have noted above, hospice ideology considers care practices as complex actions including psychological and social assistance. From this point of view, hospice care in the Russian regions looks fundamentally different both from the West and Moscow model. It is carried out in conditions of extreme poverty, as well as a non-effective Soviet social policy system. On the one hand, care in such contexts presents a complex problem for the state. The state cannot clearly see the results of care practices that are not objectified in numbers (statistics) and do not have clear bureaucratic Key Performance Indicators: what does good death mean? My informant said:

Bureaucrats do not understand what care is. They only know about a list of material objects: bed, diaper, cream. But this is good too because in many hospices even those things did not exist. Activists can report on this and this can be seen in the public domain. Also, care is not visible. Therefore, one writes complaints, for example, that there are no beds, and they provide them.

On the other hand, patients do not have the necessary conditions that allow and encourage them to think about their death in terms of dignity and autonomy. The majority of the population in Siberia live in extremely poor conditions. For instance, they have no sewage systems in their houses, suffer from high unemployment and lack of leisure infrastructure. My informant said:

The main problem is that it is not clear how to talk about dignity with people. Many have no toilet at home, it is located on the street. Can a hospice be better than their usual living conditions? They are used to the fact that any help and care can only come from the state and is expressed in concrete material things. It's literally like a Soviet grocery set in an era of scarcity.

Therefore, it turns out that the perception by both groups (patients and local authorities) of care (and receiving care) takes the form of primary resources (food and medicines), only after making official complaints. This is a form of communication between the state and its citizens formed by Soviet social policy. Hospice activists perform the following function under such circumstances: they contact the dying/their relatives and tell them about the resources they can get from the state. In this way, the practice of care no longer includes spiritual and psychological aspects, unlike in the West or Moscow, and instead becomes mediation between the state and patients in order to facilitate their receiving of government assistance (food, medicine, pensions). The state accepts and understands the format and logic of such demands because these requirements are expressed in language that is sufficiently understandable for the bureaucratic system. These may include repairs of the room, bed or bedside in hospital wards, provision of medical supplies and so on. Local bureaucracy responds easily and quickly to such complaints because they have a clear material response, while requests for non-material forms of care can be difficult to deal with. Russian sociologist Oleg Zhuravlev connects such a setting with the pragmatism of Soviet culture of distrust where ordinary people do not believe in the government and believe only what they can observe, including material objects. So, any public discourse about care can only be understood by patients and local authorities if it is associated with specific support in terms of food, medicine, furniture etc. Thus, the very concept of 'death with dignity' is to some extent reduced to provision of primary social assistance and to some extent, 'care' itself turns out to be expressed only in material form. Some of the resources obtained for patients by charity funds are simply stolen and resold. Resources that charities went to great effort to secure for hospices fell into an institutional value trap and perceived as a gift to be used at the institutions' discretion. Whatever the state provides is regarded as a gain or gift. In addition, patients consider any charitable donations as a win over the state. My informant said:

It turned out, of course, to be more complicated. We thought that we would create decent conditions and people would be happy, they would understand how to live and die. But in fact, it turned out that they perceive care as a gift. They just take it for themselves and do what they want: for example, they sell it.

Care for the dying in modern Russia faces the need to change the values and institutional environment that would allow the practice of humanising the social policy of modern Russia. My informants told me: 'I don't know what to do so that people can understand that we want to help them. This is probably a long process until the time when caring for the dying becomes the norm, and human life and its quality will be perceived as important'. It is significant to note that the Catholic organisation Caritas, that established and equipped the first hospice in Siberia in 1991, eventually reduced its programme and limited its training to individual home care. According to Caritas workers, this first hospice was conceived as a starting point for the Siberian hospice movement. However, after 15 years the head office in Germany realised that the hospice was not functioning as it should:

We started and equipped this hospice, supported it for a long time, and then gave it to the local government, remaining there as volunteers. However, the hospice has ceased to be maintained, everything was stolen and sold there. Things that were not sold were just broken. It was terrible.

Federmesser's 'posts of disappointment', mentioned at the beginning of this paper, caused serious discussion in the professional community simply because it touched upon a rather painful issue. If a certain model is quite easily cultivated specifically in Moscow, then it is obvious that the regions have their own circumstances caused by the general low-income context. The first observable consequence of adaptations to circumstances is the creation of a hospice model that functions as a mediator between government and patients. By 2019, though, hospice activists in the regions found their place in the general social policy structure. However, now they face another problem. What should they do next in order to consistently implement the idea of a hospice movement? Do they have to change their methods?

Discussion and conclusions

By the beginning of the 20th century, favourable conditions had formed for the emergence of the hospice movement in the Russian Empire. However, serious ideological and social changes brought about by the October Revolution made further developments in that direction impossible. After the collapse of the USSR, Russian society was in a difficult position, as it was lacking institutions and infrastructure needed for hospice care to be built upon. Over the next 20 years, care for the dying was implemented as targeted projects in different regions and it was often done in the form of an imported product brought by foreign activists, but there was no large-scale government action.

However, from 2011 the hospice movement began to develop. In this article, I showed how the failure of political protests in 2011–2012 led to the departure of a sufficiently large number of former political activists to various social projects, one of those being the hospice movement. Subsequently, the hospice movement began to actively develop, but never as a single model; there appeared to be two parallel projects – a so-called 'Moscow hospice model' and a 'regional model'. The Moscow model has been implemented in fairly favourable conditions brought about by high levels of wealth, value foundations and features of the local political system. However, the regional system quickly faced a set

of difficult challenges. These challenges, both social value-based and institutional, not only change the form of the hospice movement in the regions but also impart new functions of hospice activity. Instead of comprehensive care for the dying, hospice volunteers perform the function of a mediator in channelling 'in-kind assistance' from the state. Contemporary Russian hospice care in the regions finds itself in a situation of constant bargaining with the state serving as a provider of social services. Overall, Moscow and regional political activists found themselves in different conditions and respectively built different models to the point where they now don't understand each other. The question then arises, will this difference matter for the future development of the hospice movement in Russia?

We know that the development of hospices outside of the Western world has been faced with serious problems over the years (Bermeo, 2002). We do not know exactly how or why some local volunteer initiatives come to play a key part in national healthcare systems. What makes some attempts to establish hospice care successful while others fail? We know some success stories: integration of grassroots hospices into the national healthcare model in Britain (Clark, 2002) and fruitful collaboration between catholic organisations, local activists and the state in Poland (Krakowiak et al., 2016). At the same time, we also know of failures: Indian hospice experience in the Kerala state never grew beyond a local initiative (Davaasuren & Ferris, 2018; Kumar, 2013) or the example of Germany where, despite large financial input, authorities cannot level up palliative care (Escobar Pinzón et al., 2010). What steps have to be taken in the long-term to establish a comprehensive national system from a local social initiative? In this process, researchers note a large number of different contributing factors such as culture, economic situation, traditions, and infrastructure (Brereton et al., 2017; Clark, 2002; Exley, 2004; Lockett et al., 2014).

The main aim of this article was to show not only the importance of certain structural characteristics that can influence the formation of hospice care and creation of a hospice movement but also the importance of individual actors and events that can become catalysts for change. The case of the hospice movement is especially interesting in this regard because the ideology of the movement is politicised. However, there remain issues for future attention. How can hospice ideology be realised in authoritarian states and low-income contexts? How should human rights discourse be re-conceptualised in impoverished communities?

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

Research supported by Oxford Russia Fellowship (2018-2019) and the 'Khamovniki' Foundation

Notes on contributor

Sergei Mokhov PhD in sociology (HSE, Moscow), is a Research Fellow at The Institute of Ethnology and Anthropology, Russian Academy of Science, and author of the book *The birth and death of funeral industry: from the graveyards to the digital immortality* (Moscow: Common place 2018; in Russian). Oxford Russia Fellowship (2018-2019).

ORCID

Sergei Mokhov  <http://orcid.org/0000-0002-6400-7100>

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