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Narrating and remembering as practices of care, community, and commitment in asbestos contaminated contexts

Agata Mazzeo

Dipartimento di Storia Cultura Civiltà, Università degli Studi di Bologna, Bologna, Italy

Abstract

In contexts of social and environmental disasters, practices of memory and narration can become actions implemented by the affected groups to cope with the suffering related to the disaster experience, to mobilise in the name of social justice, and to favour those dynamics by which the survivors develop their sense of being part of a community. This article is based on qualitative data collected through an anthropological study based on ethnographic fieldwork conducted in Italy and Brazil. It discusses the practices by which the survivors of the impact of asbestos-related disaster on their lives make sense of their suffering experience and engage in a grassroots health-based movement. Attention is paid on the social aspects of the health impact of asbestos exposure, and the role of the affected communities in the elaboration of their own paths of care by remembering and communicating the disaster is considered.

Key words

- asbestos
- grassroots activism
- health hazards
- ethnography

INTRODUCTION

In contexts of social and environmental disasters, practices of memory and narration can become actions implemented by the affected groups to cope with the suffering related to the disaster experience, to mobilise in the name of social justice, and to favour those dynamics by which the survivors develop their sense of being part of a community.

This article is based on qualitative data collected during a "multi-sited" [1] ethnographic fieldwork conducted in Italy and Brazil with communities living in asbestos contaminated urban sites.

For a description of asbestos health impact, the reader is referred to the paper by Marsili *et al.* [2] in the same issue. According to the list provided by the International Ban Asbestos Secretariat (www.ibasecretariat.org/), 65 countries have prohibited asbestos to date. Italy has prohibited it in 1992, while Brazil, with an asbestos chrysotile mine still in function, has banned asbestos only by law in December 2017. Due to the burden of asbestos worldwide, the health effects of asbestos exposure can be considered as a public health disaster of global dimension.

This article refers to the practices by which the survivors of the impact of a similar disaster on their lives make sense of their asbestos-related suffering and engage in a grassroots "health-based social movement" [3]. The data discussed below emerged from an ethnographic fieldwork conducted in four research settings: Bari, Casale Monferrato, and Bologna in Italy, and Osasco (São Paulo) in Brazil. The data show in what extent, in the investigated contexts, remembering and narrating the past coincided with practices of socio-political commitment in a movement aiming at the recognition of an invisible disaster and at the global prohibition of asbestos. Moreover, the act of narrating represented a possibility of encounter and openness to the "other" that became a possibility of care for a suffering that was perceived as individual and private as social and collective.

This article aims at paying attention on the social aspects of the health impact of asbestos exposure and considers the role of the affected communities in the elaboration of their own paths of care by remembering and communicating the disaster. By discussing various practices of memory and narration as strategies of care and activism rooted in distinct socio-cultural contexts, this article shows the importance of understanding existing differences across languages, meanings, and actions as a crucial and preliminary step towards effective communication among stakeholders from civil society, researchers, and public health professionals from distinct backgrounds and with distinct expertise. In fact, bridging cultural gaps among all the social actors involved in a disaster process is essential to understand, face and prevent health disasters, especially those that are slow, invisible and often not recognized as are the disasters provoked by the toxic market of asbestos.

Address for correspondence: Agata Mazzeo, Dipartimento di Storia Culture Civiltà, Università degli Studi di Bologna, Via Zamboni 33, 40126 Bologna, Italy. E-mail: agata.mazzeo2@unibo.it.

MATERIAL AND METHODS

The material here presented consists of quotations from fieldnotes and in-depth semi-structured interviews conducted with anti-asbestos activists from the four research settings where the Author performed an anthropological study on the relationship between a person's experience of asbestos-related suffering (i.e. illness, contamination, and grief) and the engagement in the anti-asbestos movement. The encounters with the study participants occurred between 2009 and 2018, and took place in occasion of various steps of fieldwork (each lasting from two to ten months) and field trips due to ongoing research.

Participant observation was performed during attendance of the local anti-asbestos Non-Governmental Organizations (NGOs) organised by asbestos exposed and their relatives, with whom the researcher has been collaborating in all settings.

Upon the free and informed consent of the interlocutors, the interviews have been digitally recorded, then transcribed, analysed and translated by the Author since the interviews were performed in Portuguese and Italian languages, without the support of an interpreter.

Historiographical and archival research have been performed to contextualise the collected data in each local socio-political and cultural context.

Bari

In Bari, the capital town of Apulia region, Southern Italy, the main asbestos polluting source was the "Fibronit site", a 100 000 m^2 area situated in a densely populated neighbourhood where an asbestos-cement plant, the Fibronit, has been functioning from the early 1930s to the late 1980s [4]. The plant was then abandoned and kept contaminating the environment until the 2007, when the site, recognized as a contaminated site of national priority for remediation, was partially reclaimed. In 2017, the work for complete reclamation, demolition and construction of a public garden finally began.

Fieldwork in Bari was performed in May-October 2009, and the research focused on the illness experience lived by men and women who developed malignant mesothelioma because of environmental exposure to asbestos. According to interlocutors' narratives, the diagnosis was often achieved with relevant delays implying serious consequences in terms of treatment's effectiveness and patients' distrust towards biomedicine. Moreover, an apparent non-existent connection to the factory prevented the persons with malignant mesothelioma contracted by environmental exposure from relating their own suffering to asbestos exposure, and from counting on a social support by the local unions.

The following quote is from a Skype interview occurred in May 2012 with a researcher's key interlocutor from Bari, who was one of the founders of the local anti-asbestos NGO. The interview is discussed in further detail elsewhere [5].

She [the interlocutor's wife] *decided to launch a blog where we would post all the information that we were collecting about malignant mesothelioma, asbestos, and the recovery of the Fibronit site. However, in the beginning, she was not completely sure… she was very angry when she got the diagnosis, and I was more active on the blog. When she began to feel better, after the surgery and the first cycles of chemo and radiotherapy, she began writing about her experience and her feelings. She thought that in that way she could help others going through similar experiences. Many began to contact us. The blog was offering a sort of help to people feeling frustrated, disoriented, and abandoned as we were.* […] *We wanted to promote a network through which people could share information, and be advised about what to do once received the diagnosis.* […] *I still have my wife's phone with all the numbers of men and women with malignant mesothelioma with whom she was in contact. Many of them were from other cities. They talked about their experiences by sharing opinions, fears, and hopes.*

Casale Monferrato

In Casale Monferrato, a town of 35 000 inhabitants, the largest asbestos-cement plant owned by the Eternit firm in Italy operated over 80 years, from 1906 to 1986 [6]. In the same Region, Piedmont, the largest asbestos mine in Europe, the quarry of Balangero, provided the national and international asbestos market with almost four million tons of asbestos produced throughout the 20th century, according to the World Mining Data 2008 [7]. The ReNaM reports 3560 malignant mesothelioma cases registered between 1993 and 2012 in Piedmont Region [8]. Asbestos-cement production at the Eternit in Casale Monferrato is recognised as the main cause of the death of almost 2000 men and women from asbestos-related diseases contracted by occupational and/or environmental exposure to asbestos in the city, since the start of the activities at the Eternit factory to the recent years [6].

Starting from the early 1980s in Casale Monferrato, the increasing number of people diagnosed with, and dying from, asbestos-related diseases triggered a worker and civil mobilization that led to the promulgation of the first law prohibiting asbestos containing products in Italy [6]. Over the years, the anti-asbestos movement in Casale Monferrato has reached other important achievements with a social relevance on the local, national, and international level. Among them, there is the organization of the first trial against an asbestos-cement corporation accused of environmental disaster manslaughter [6].

An interactive laboratory designed to narrate, in parallel, the tragedy of the disaster and the local mobilization of citizens and workers begun in the early 1980s to denounce the health effects of asbestos exposure was inaugurated in November 2014 in Casale Monferrato. Teachers, students, and the local anti-asbestos NGO have been the main social actors lobbying for the foundation of the laboratory. A comprehensive review of epidemiological studies performed in Casale Monferrato and the social, educational and community-oriented initiatives is presented in the paper by Marsili *et al.* [2], in this same issue.

In Casale Monferrato, ethnographic fieldwork was conducted by the Author in May-June 2012. Afterwards, several fieldtrips occurred. Below, a quote from an interview conducted in June 2016 with an anti-asbestos activist who collaborated with the team of

professionals who realised the interactive laboratory is reported:

Our main concern was to leave a testimony. Our prior objective was to pass the baton to someone else willing to collect this testimony and to become him/herself a spokesperson not just of what happened in relation to asbestos, but in a broader sense, in relation to a different idea of development. It should be questioned whether it is worth pursuing a development that brings immediate profit for few people, and leaves a terrible legacy for millions. It should be promoted the idea that you cannot achieve economic development without thinking of the consequences that it leaves on the environment, and we should let these ideas sprout up among younger generations, among those who will take decisions in the future. […] I am deeply touched when I see students' passion and commitment. They learnt to share emotions, not just the contents. This is the result of years of work and awareness campaigns, but it is also the sad consequence of the disaster. Among the most motivated, in fact, there are those who lost the grandpa, the father, or the mother. Unfortunately, the personal experience of the suffering is decisive in triggering one's engagement.

Osasco

Osasco is a city with approximately 700 000 inhabitants bordering the megalopolis of São Paulo. Since the 1940s until the late 1970s, Osasco lived a frantic industrialization and became home of various national and multinational industries, including the largest asbestos-cement plant of the Eternit brand in Latin America, operating from 1943 to 1993 [9]. The local anti-asbestos NGO was founded in 1995 by a group of former asbestos exposed workers, the majority of whom had worked at the Eternit, who found themselves contaminated with asbestos after the factory's closure in 1993. In a country such as Brazil where asbestos has been prohibited by law only recently (in December 2017), but it is still used, the anti-asbestos mobilization focused on the promotion of a dialogue with biomedical professionals from local occupational health centres, national research institutes and public hospitals, while pursuing the national asbestos ban. To achieve that, Brazilian anti-asbestos movement is still engaged in the deconstruction of the paradigm stating the safety of asbestos controlled-use, and to contrast the phenomenon of asbestos-related diseases' under-diagnosis as it happens to be a frequent phenomenon in countries currently using asbestos [10]. In Osasco, an ethnographic fieldwork of ten months was conducted in two phases, in August-October 2014 and February-October 2015.

In Osasco, every year, on an early Sunday morning of April, i.e. the month internationally dedicated to occupational health, a group of men and women of various ages and religious beliefs gather in the shadow of majestic trees, in a tiny circular square. The square is bordered by a wall on which the bystanders sit and, at the centre of which, a stone altar stands. The square is called *Praça Aquilino dos Santos - Vítima do Amianto* [Asbestos Victim], in memory of the first asbestos exposed worker who died after the local anti-asbestos NGO's foundation in 1995. The meeting represents the final event of a week of activities organised by the local anti-asbestos activists to raise awareness of asbestos dangers among general population.

The Author participated to the campaigns and actions performed in April 2015. During the collective commemoration, anyone could take the floor and remember a beloved one deceased due to an asbestos-related disease. Fragments of life then resurfaced from the words and emotions of those who survived and were still mourning an irreplaceable loss. At the Eternit in Osasco, the workers were all men with the exception of few women working in the administrative sector. This explains why the majority of the recalled names and fragments of life referred to a lost husband, brother, or father.

Below, a quote from the Author's doctoral dissertation [11] resulting from her fieldwork in Brazil is reported, and it is based on the fieldnotes written soon after the above-mentioned commemoration. *Figure 1* was taken by the Author on the morning of the collective commemoration and refers to the following quote.

During the ceremony, I felt like I was witnessing (and participating in) a sacred ceremony. I was particularly struck by the photographs of the activists who had died and whose portraits were exhibited and hanging just behind their survivors. The glances of those men and women about whom I had hear from their loved ones' narratives seemed to assert their presence and participation beyond their physical and irreversible absence. Part of the ceremony was dedicated to the commemoration by spontaneous sharing of memories and feelings: everybody could speak and say something about a friend or a relative who had died. […] Remembering was painful, but was felt as necessary and conceived of as a moral and political commitment.

Bologna

In Bologna, in Casarini Street, number 25, there are the Officine Grandi Riparazioni-OGR, one of the largest railway repair factory owned by the national railway company. Among the disparate uses of asbestos in Italy before its prohibition, there was a massive utilization of asbestos in the railway industry, especially in the brake systems' production, wagons' insulation, and repair. At the factory set up in Bologna in 1908 and closed in

Figure 1
Commemoration of asbestos victims, April 2015, Osasco (São Paulo, Brazil). Photograph by Agata Mazzeo.

2018, thousands of workers have repaired hundreds of damaged trains throughout the 20th century. The Author visited the OGR on April 28, 2017, on the day internationally dedicated to the victims of asbestos exposure. At that time, the company had already decided to dismantle the factory and the huge site seemed a ghostly industrial landscape.

During the ceremony in memory of asbestos victims, in addition to a sorrowful commemoration of comrades and colleagues who had already passed away, asbestos exposed workers, the majority of whom were members of the local anti-asbestos NGO, pronounced discourses evoking the role of another important subject of their individual and collective stories, the OGR site itself. That was the place where they had nurtured their aspirations and dreams as young men enthusiastic of their job, and which turned to be associated with the most awful of their nightmares in the present. The threat that their past and memory might be vanished together with the tangible proof of their endured injustices triggered in the exposed workers the urgency to elaborate and put into practice new strategies of struggle. To date, they are currently mobilising to defend their "cultural space of memory", and their right to live the "remembering experience" [12]. In particular, the mobilization is currently aiming at entering the decision-making process on the future use of the site to be recovered and preserve a museum set up by workers in a part of the factory throughout the years.

The ongoing collection of ethnographic data in Bologna started in November 2014, when the Author began a collaboration with local anti-asbestos activists to raise awareness of asbestos dangers by organising educational projects at local public schools. A quote from an interview conducted with a worker who was one of the main museum's curators and who is now lobbying for the museum's reopening in the name of the workers right to remember and narrate their story is reported below. *Figure 2* was taken by the Author in occasion of a visit to the workers' museum on April 28, 2018.

I fell in love with the factory's story, a story of sweat and fatigue, but also of pain. I began collecting everything that recalled that story: objects, documents, and photographs. I needed to find a place where memory could be saved. I had to do that because of my friends and co-workers with whom I had shared a piece of my life and who died in their 50s. […] I terribly suffered for their loss, and every day I renovate my commitment not to forget them.

Over the years, the museum has become the proof of what everyone tried to deny, that was the extermination of many friends and colleagues. All the documents from the medical surveys and the judicial trials as well as the objects we had collected made impossible for anyone to deny the history of the factory and delete the memory of our friends and co-workers. […]

Since the closure of the factory, in June 2018, I feel a deep and indescribable void exacerbated by the impossibility to visit the museum, to see with my eyes and touch with my hands what was part of my life. I miss touching a screwdriver or a plane, looking at the yellowed photos hanging on the museum wall, or taking a moment to reflect while looking at the self-made equipment used to try to protect ourselves from asbestos in those that should be our safe working places, but they were not. […]

In the museum, I could see the tangible achievement of my main purpose, which was to break the silence about our story. For me, there will be no peace until the museum will be reopened and made accessible to everyone. I will fight until my body and my mind will support me to see the museum opened again and the factory's site turned into the shrine of the martyrs, my friends and colleagues, executed in the name of profit. The museum then will be a sort of compensation for the victims of that massacre, a place of meditation and warning for the future.

Figure 2
Objects from the collection of the museum set up by the workers of the Officine Grandi Riparazioni-OGR, April 2018, Bologna (Italy). Photograph by Agata Mazzeo.

DISCUSSION

A narrative performance is always influenced by the context in which it occurs, by the objectives pursued by the narrator(s), and by the affects exchanged with the audience [13-15]. It is always relational, contingent, and negotiated. It can use various languages, styles, and registers. It helps to build an individual as well as a collective identity [16]. It can become a "tool", strategically and politically used, to save memory, to promote actions, and to make the suffering lived by entire communities visible notwithstanding the lack of general recognition of it.

The above-presented data show the entanglements among the (collective and individual) disaster experiences, the meanings attributed to "places of memory" [12, 17] and narratives, and the socio-cultural context from which they emerge.

In Bari (Italy), the social actors involved in the disaster experiences had to make sense of an exposure that had persisted ignored until the diagnosis of the fatal cancer, the malignant mesothelioma. Data analysis showed that this aspect deeply influenced the local anti-asbestos activism, one of whose main purposes was overcoming the loneliness and the abandonment perceived by people with malignant mesothelioma and their relatives while facing the uncertainties related to the diagnosis, and the difficulties associated with painful and ineffective treatment.

In a similar context, the first action ideated by the founders of the local anti-asbestos NGO was to narrate and divulgate narratives of asbestos-related illness experiences through a blog. The blog soon became a reference point for whom was searching information about malignant mesothelioma on the Internet, and new relationships – and "biosocialities" [18] – emerged from sharing experiences, knowledge, and emotions triggered by a bodily condition of suffering.

As extensively discussed in the paper by Marsili *et al.* [2] in this same issue, in Casale Monferrato, the interactive laboratory has been conceived of as a "black box" containing proofs, memories, and stories of disaster as well as of the workers and citizens' mobilization. Differently than in Bari, where the links with the world of the factory were narrated as completely unperceived by the study participants, in Casale Monferrato the local anti-asbestos NGO operated in strong collaboration with the local trade unions. The processes through which the disaster extended from the factory to the whole city had been made visible in Casale Monferrato thanks to a grassroots activism able to mobilise and strategically use local social structures and expertise in collaboration with unionists and public health researchers from local unions and hospitals.

The high awareness of asbestos dangers developed among Casale Monferrato's inhabitants represents one of the most important achievements reached by the anti-asbestos activists. The stories of suffering and struggle have come to be narrated not just by local social actors personally involved in the disaster experience, but also, for example, by journalists, writers, photographers, and video-makers communicating the disaster and the workers and citizens' mobilization to a large audience.

The team of professionals including architects, designers, and photographers who realised the interactive laboratory, took almost one year and a half to set it up. At the laboratory, the twelve chapters through which the collective story of Casale Monferrato as the "city that fights against asbestos" [19] is narrated have been "written" after having consulted local social actors and experts in subjects approaching asbestos-related issues from multiple perspectives, e.g. historical, biomedical, and geological. At the laboratory, there is also a section where twenty stories of men and women remembered and narrated by their loved ones are collected.

In Osasco (Brazil), the subversive tension intrinsic to the acts of remembering through narration dissolved the fracture between past and present, and represented practices of a prolonged individual and collective mourning turned into a form of resistance. On this regard, the anthropologist Zhang [20] has highlighted how "the refusal to end mourning becomes a political action of protest against the social injustice responsible for the loss of life. In this light, death is no longer accepted as the end of a life, but is scrutinised as the beginning of the pursuit for justice. The gravity of mourning moved away from death toward life along the axis of moral responsibility for the loss" [20, p. 271].

In Bologna, a "community of memory" [12] is currently aiming at turning a contaminated/contaminating site, dense of meanings for those who had worked there, into a living memorial in the name of social justice. Local anti-asbestos activists assumed the moral commitment not to forget their friends and colleagues who died of asbestos-related diseases. By borrowing from Foucault [21] the effective and suggestive concept of "heterotopies", the space devoted to the memory will then become a heterotopy of resistance where the past/present fracture will be subverted. The past and the absence related to irremediable losses will then become an intense presence, and a place of death will turn into an affirmation of life, since "survival [to a disaster] is the most intense life possible" [22]. The industrial site is meaningful for the community of survivors that, in the present, is able to identify in it the symbols of its story and the traces of its past [17]. From keeping a shared past alive, a community that has been affected by the disaster can elaborate its identity and imagine new practices and meanings to give sense to a destroyed world. The places and the objects then become symbols of a shared past and the tangible proofs of the subtle violence endured over the years. The possibility of touching or looking at the traces of the past allows the survivors to reflect on their individual and collective stories and elaborate their own narration as the retired worker interviewed in Bologna mentioned.

CONCLUSIONS

In all settings here presented, the practices of memory and narration appeared to be crucial: remembering and narrating the disaster represented a strategy of struggle and favoured the elaboration of a "collective memory" [23] based on which a community was emerging and building its identity [17]. Halbwachs highlighted how dynamics and relationships that take place in the present influence memory [23], and the Italian anthropologist Ugo Fabietti recalled Halbwachs' qualification of memory as "communicative" to emphasise its being always a social, and relational practice [17, 23].

Practices of memory and narration are simultaneously practices of care, community, and commitment in the extent to which social actors involved in asbestos-related experiences of suffering due to disease, contamination and grief refer to a collective and individual past to reconcile with (and change) a familiar world that has become a source of sorrow, loss, and threat. By engaging in the activism, the "sufferer-activists" [11] reinvent the world wherein they act, negotiate their identity, and establish new affective relationships.

Remembering and communicating memory correspond to intentional acts and are dependent upon a will that is always historically and culturally informed [17]. The practices of memory and narration show their therapeutic effect for the disaster survivors as both individuals and members of a community. In a similar pathway of care, the "places of memory" [virtual or physical i.e. an industrial site, a museum, a collective ceremony, or an Internet blog) are crucial in the extent to which they favour the "remembering experience" [12] and become cultural spaces for the collective and individual narration of a shared story. In this way, individual experiences of suffering are situated in a broader story of injustice and disaster, and acquire meaning in a continuity with the past.

Taking into account the specificities of each context, the communities living in the four asbestos contaminated sites considered in this article have all been affected by the silent and slow disasters associated with the toxic market of asbestos. Beyond the distinct meanings and words of the collective and individual narratives elaborated by the community members with whom research was performed, a common aspect has been grasped. "Sufferer-activists" [11] from each context conceived remembering and narrating as necessary practices to adhere to a moral commitment assumed in front of the next generations while they were still mourning the irremediable loss of their beloved ones who died of asbestos-related diseases.

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