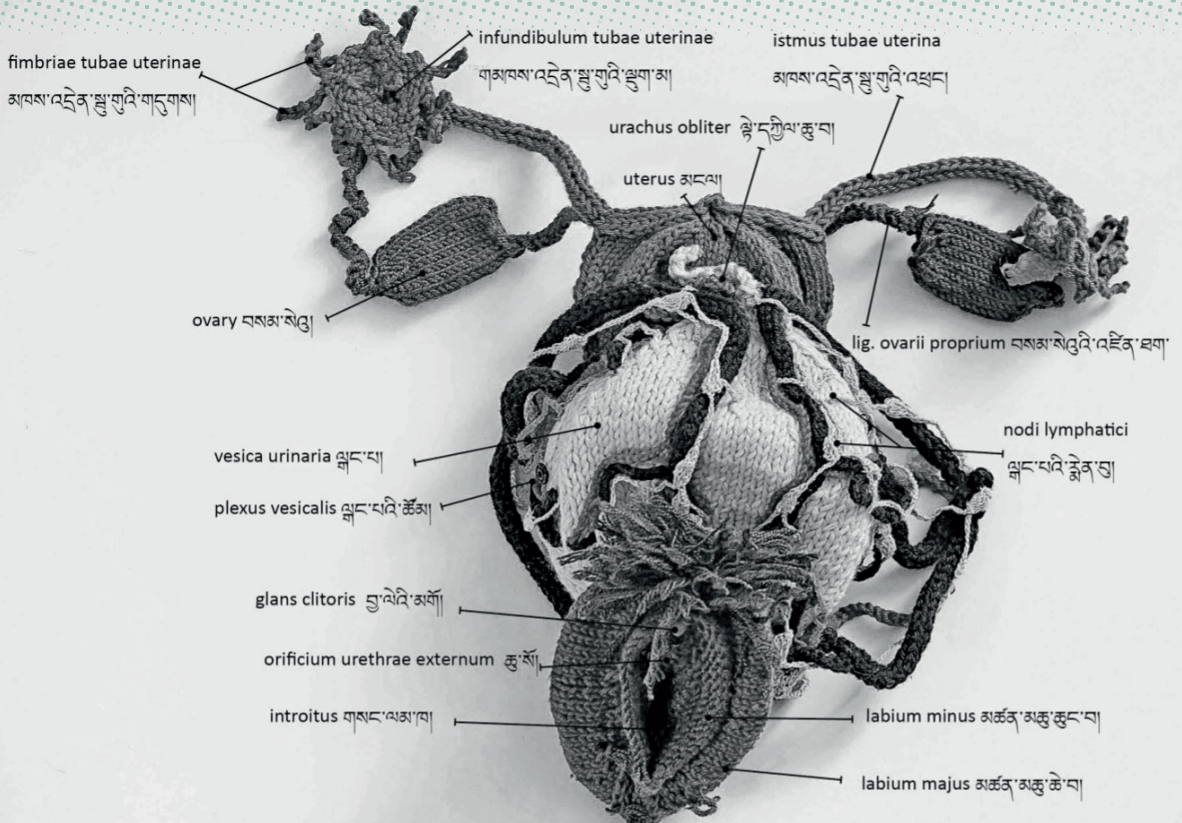


Curare

Visuelle Ausdrucksformen von Gesundheit, Krankheit und Heilung

Visual Expressions of Health, Illness and Healing





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Editorial

We are delighted to present with this issue selected results of the 34th conference of the Association for Anthropology and Medicine (AGEM), which took place in cooperation with the Austrian Ethnomedical Society (Österreichische Ethnomedizinische Gesellschaft, ÖEG) and the Weltmuseum Wien in Vienna from June 2 to 4, 2022.

The conference entitled “Visual Expressions of Health, Illness, and Healing,” was co-organized by Katarina Sabernig, who is also the guest editor of this issue’s thematic focus. The conference was conceptualized as a follow-up to the 32nd AGEM conference on “Aesthetics of Healing” in Münster

in 2019 and focused on visual forms of expressing and communicating aspects of health, illness, and healing in clinical, educational, socio-cultural, and subjective contexts (cp. the conference report in *Curare* 45(2022)2).

We would like to thank Katharina Sabernig and the other board members of the ÖEG as well as the team of the Weltmuseum Wien for their cooperation and kind support in facilitating such a diverse, interdisciplinary, and enriching conference and experience.

Curare Editorial Team

SCHWERPUNKT
THEMATIC FOCUS

Expressions of Health, Illness and Healing

EDITED BY
KATHARINA SABERNIG

Visual Expressions

Introduction

KATHARINA SABERNIG

From 2–4 June 2022, the 34th Annual Conference of the Association for Anthropology and Medicine (AGEM) took place in Vienna in Cooperation with the Austrian Ethnomedical Society and Weltmuseum Wien. Entitled *Visual Expressions of Health, Illness and Healing*, the conference was open for presentations dealing with the visualisation of medical topics in various ways from different perspectives. The conference was inter- and transdisciplinary with a focus on visual medical anthropology and the transcultural medical humanities. The participants were researchers in social sciences, artists, curators, as well as medical practitioners, their patients and the patients' relatives. The conference was also organised in memoriam of the late physician and medical anthropologist ARMIN PRINZ who founded the Austrian Ethnomedical Society and initiated the Ethnomedical Collection including objects, materials and paintings representing various aspects of health in different medical cultures. The Ethnomedical Collection was formerly located in the historical building “Josephinum” and was donated to the Weltmuseum Wien in 2017 (<https://www.weltmuseumwien.at/>). Therefore, the exhibition *Donation of the Austrian Ethnomedical Society – A Selection of Popular Paintings from Kinshasa, Democratic Republic of the Congo* (2 June–1 November 2022) was curated and opened in the scope of the conference. HELMAR KURZ und KATHARINA SABERNIG published a detailed report on the conference in *Curare* 45 (2022) 2: 97–106.

The AGEM conference was regarded as a continuation of the previous conference *Aesthetics of Healing: Working with the Senses in Therapeutic Contexts* which took place in Münster in 2019 and about which a report was published and edited by HELMAR KURZ in *Curare* 42 (2019) 3+4. After the pandemic interregnum a call for papers was opened in November 2021 and invited contributions involving simple sketches, vivid comics, elaborate paintings or computer-aided simula-

tions, to name just a few possibilities, that are used to illustrate medical topics that are often difficult to access through language alone. The aim was to explore the manifold ways of visual and artistic expression in the context of individual healing, education or social awareness. This issue is a selection of contributions of authors who presented in person or had submitted an abstract but finally could not come.

Depending on the setting, purpose and audience, images may be created not only as a didactic tool to explain medical content, but also in the context of therapy and communicating individual as well as societal fear or suffering. The visualisation can contribute to a deepening of therapeutic conversation or also stand for itself as an artistic manifestation. Visual expression can take place in the context of therapy, and as form of self-reflection during educational training of prospective medical professionals rooted in their medical field and respective cultures as well as on a broader societal stage. Medical humanities regard visual arts as a powerful tool for public engagement, which also showcase healthcare topics in an artistic manner (CRAWFORD *et al.* 2015: 117). This *Curare* issue is a collection of scientific articles, essays of individual or collective experiences, and conference or project reports. Together they present a variety of aims, approaches and artistic expressions from different educational backgrounds.

Articles

In a nutshell, this issue starts with two articles dealing with educational examples from Asia. BARBARA GERKE examines a Tibetan medical thangka (scroll) which illustrates knowledge on “infectious diseases” in the seventeenth century. ELIZABETH TURK's article documents the visuality of Mongolian public health campaigns in the context of “being cultured” with a focus on the corona pandemic. A more personal aspect of health

visualisation is presented by SASKIA JÜNGER & MARIYA LORKE in “Visual expressions of embodied risk,” who conducted narrative interviews with individuals who have an increased risk for certain diseases and were invited to sketch their risk on body maps.

Visualisation of medical content for the purpose of communicating information or improving communication is demonstrated in all three articles. Individual reflections on the visualisation of conditions that are otherwise difficult to describe is at the centre of the following two essays. BARBARA GRAF reflects on her artistic PhD project wherein she visualises the bodily sensations of her own multiple sclerosis disease. ILEANA SZASZ documented the ongoing development of the dementia of her father as a filmmaker and anthropologist. The Essay by SARA VALLERANI and her team gives insight into the creative group process, inspired by the situation of lockdowns during the pandemic in Italy. In the Reports section we have four reports on activities regarding artistic medical humanities. ANDREA PRASCHINGER *et al.* present the didactic considerations and development of an inspiring medical comics project within the hospital at the Medical University of Vienna. CÉLINE KAISER reports on the development of medical humanities activities within IMHAR, a space which combines the approaches of artistic research with those of medical and health humanities. KATHARINA SABERNIG gives insight into the results and the conference of the “Comparative Guts” project, a further group work on the diverse ways in which the body’s interior has been depicted throughout time and space and she reports on her own artistic research project.

BARBARA GERKE’s and ELISABETH TURK’s articles examine the visualisation of didactic medical content, authored by historical and contemporary Asian health Institutions, and addressed to anonymous viewers to transport information. GERKE’s article “Visual Dynamics of Contagion: Poisons and Antidotes in Tibetan Medical Paintings of the Seventeenth Century”, refers to a scroll painting included in a set of Tibetan medical thangkas. It was created at the eve of modernity not only for medical students but also for a broader public during an important historical period, namely the rise of the Fifth Dalai Lama’s Ganden Podrang Government in Lhasa (cf. PARFIONOVITCH *et al.*

1992; GYATSO 2015). She analyses the dynamics and relationship between poisons and antidotes used to treat poisons and questions the multi-layered concept of pathogen transmission in the Tibetan context, in the core of which is a myth of Indian origin.

Another form of visualisation in the scope of contagious diseases on behalf of a government was examined by TURK with her contribution “‘Being Cultured’, Changing Culture: public health messaging in COVID-era Ulaanbaatar”. Her observations took place not far north of Tibet, in Mongolia, and bring us to a contemporary world, which at the time of the conference was still dominated by measures and dynamics of the pandemic. TURK shows images of a health campaign alongside LOUIS ALTHUSSER’s work on ideological state apparatuses. In addition to visualising measures to prevent the transmission of the virus, the campaign also aimed to promote good behaviour and avoid misbehaviour, such as avoiding urinating and spitting in public.

Yet another goal of visualisation is investigated in a research project by SASKIA JÜNGER & MARIYA LORKE entitled “Visual expressions of embodied risk – body maps as a means of reflecting and understanding the meaning of health risk in research and teaching”. Instead of using body maps to communicate an abstract likelihood of risk that an individual will get a certain disease they inverted the principle and tried to visualise the impact for an individual or the general meaning of a certain risk of disease. They interviewed 20 people affected personally with a diagnosed higher risk of familial breast and ovarian cancer or psychosis and invited them to draw their individual risk on a body map. In the scope of an ethics seminar they also invited medical students to imagine the risk for selected case in a similar way. They conclude that the use of body maps can help patients and participants to reflect on and understand embodied health risks (see also: LYS *et al.* 2018)

Essays

The essay “Visual Embodiments of Bodily Sensations and Their Individual Conditionality: A Visual Phenomenology” by BARBARA GRAF delves deeply into this form of visual communication in a more personal and artistic way. She visualises the sen-

sations caused by her multiple sclerosis and reflects on the influence of her artistic activity on her self-perception. The drawings not only convey the quality of her paraesthesia but also its intensity in the sense of dolography, similar to pain scales (cf. AFFOLTER & RÜFENACHT 2018; MELZACK, RONALD & TORGERSON 1971). In her work she is not only reflecting on her own experiences but also conveying the invisible sensations to other affected individuals, such as relatives and medical professionals. These quantitative and qualitative scales of sensations have the potential to be used diagnostically to help other patients to communicate their discomfort.

In “As far as I can record. Constructing the representations of living with dementia in a personal documentary film”, ILEANA SZASZ reflects on her relationship as a filmmaker with her father as he experiences the ongoing process of his dementia. She discusses the methodological challenges within a documentary setting while oscillating between the interchangeable roles of being an outsider (the documentary filmmaker) and an insider (the daughter). In the genre of personal documentaries the lines between public and private life are blurred (cf. AUFDERHEIDE 1997). The contribution is not only a moving documentation of family dynamics during a progressive illness but also an autoethnographic contribution on (Re)discovering and reframing familiarity.

MARTINA CONSOLONI, DELIA DA MOSTO, MARGHERITA NERI and SARA VALLERANI describe in their essay “Comics in the Time of COVID-19: Examining the Role of Graphic Medicine in Promoting the Right to Health”, the experience of creating the medical comic book *Materia Viva* in 2020. The comic book was formed by the KÄTHE COLLECTIVE, a group of scholars with different educational background, and is an open access medical graphic which does not focus on a certain disease but on health inequalities and the right to health. Though the Käthe collective was founded before the Covid pandemic the comic was born in the context and under the impressions of the first Italian lockdown in 2020. The contribution gives insight to the circumstances in which the book was developed and the dynamics of how the scholars communicated online.

Documentation

Another group project visualising medical comics took place in the Medical University of Vienna teaching centre. It was initiated by ANDREA PRASCHINGER and EVA K. MASEL and additionally carried out by RUTH KUTALEK and RUTH KOBLIZEK. Within more than three years three exhibitions on three medical topics – body, borders, and pain – have been curated by a larger team. One aim is to use the comics to provide an opportunity for reception, interpretation and reflection by viewers. In difficult clinical situations, especially in palliative care, it is important to address the unspeakable or unspoken (MASEL *et al.* 2020). Medical graphics may be a helpful tool to start conversations in difficult situations not only in the scope of relations between patient and medical professionals but also to address stressful situations in clinical practice or medical education. Various artistic contributions using different media and materials to visualise particular problems were exhibited. The project ended with a symposium: “Power of Graphic Medicine”.

Yet another initiative which combines approaches from Medical & Health Humanities and artistic research, in order to develop and encourage new perspectives on perceptions of health and illness (ANKELE & KAISER 2022) is the Institute for Medical & Health Humanities and Artistic Research (IMHAR) founded in 2020. IMHAR involves artists, cultural scientists, medical historians or activists, and, above all, people who are actively engaged in transdisciplinary creative work in these areas. CÉLINE KAISER looks back and forward after three years of activities with three different event formats: the ‘Reading Room’, the ‘Colloquium’ and the ‘Salon’ which initially took place in the digital space.

The significance of visualising the bodily interior rather than relying on textual descriptions is explored in the project “Comparative Guts,” initiated by CHIARA THUMIGER and ANGELIKA MESSNER (both Kiel University, Cluster of Excellence Roots). A year before the hybrid and in-person event took place, more than thirty visual artists, textual historians and medical anthropologists and archaeologists from diverging fields were invited to several online meetings to present as-

pects of human guts from their perspective. Organs which are traditionally linked to nutrition and digestion, were presented with their associated emotional, ethical, and metaphysical significance. With the scholarly knowledge of a diverse mixed crowd of experts three remarkable results have been achieved: an online database, a printed book and the conference itself which is reported in this issue.

The cover image of this issue is the result of a long process deeply rooted in my research on the concepts and history of Tibetan medicine and anatomical knowledge. My studies on two- and three-dimensional representations of the human body and ethical questions associated with the field of anatomy led me to the idea of knitting interior structures, which could be used as the visual basis of a bilingual Latin-Tibetan anatomical chart such as images of the intestines and female urogenital tract. Rather than focussing on current developments of the project, the report sheds light on the earlier thoughts and background of “knitted anatomy” and the close links to my examination of the development and coining of Tibetan anatomical vocabulary.

Conclusion

The conference and this issue of *Curare* were regarded as a continuation of the “Aesthetics of Healing: Working with the Senses in Therapeutic Contexts” with a special focus on the visuality of various expressions in the context of health and healing. The diversity of the individual and group contributions reflects the numerous possible applications of the visual in a health-related context. The visualisations presented in the articles are sometimes didactic, sometimes therapeutic, often oscillating between both, but the focus is always on communicating a health-related topic. These are examples of the wide range of useful applications of pictorial communication. The conference has certainly shown the possibilities of collaboration between the medical and health humanities, and that the arts could be utilised much more in clinical practice and that more research could be done in this field.

Acknowledgements

First and foremost, I would like to thank my colleagues DORIS BURTSCHER and RUTH KUTALEK and the staff of the Weltmuseum for their support in organising the conference. I would like to thank all the authors and especially HELMAR KURZ, who took over the communication with the curare editorial team and provided valuable advice. Thanks also go to CATHERINE KEMP, an English native speaker who has edited my English-language texts with great sensitivity since many years.

Notes

- 1 Käthe Collective 2021. *Materia Viva*. <https://collettivakathe.wixsite.com/kaethe>.
- 2 IMHAR. <https://www.imhar.net/en/>.
- 3 Comparative Guts: <https://comparative-guts.net/>.
- 4 Knitted Anatomy: <https://www.knitted-anatomy.at/>.

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lence Roots (https://macau.uni-kiel.de/receive/macau_mods_00004630?lang=en).

Visual Dynamics of Contagion

Poisons and Antidotes in Tibetan Medical Paintings of the Seventeenth Century

BARBARA GERKE

Abstract How does one visually depict the spread of disease? Tibetan artists at the turn of the seventeenth century must have asked themselves this very question when they prepared a series of medical scroll paintings, one of which will be discussed here. They were painted to illustrate the medical writings of the Fifth Dalai Lama's regent, DESI SANGYÉ GYATSO, specifically his commentary on the *Four Tantras*, an important medical treatise dating back to the twelfth century. SANGYÉ GYATSO oversaw the preparation of these scroll paintings in Lhasa. They were designed for educational but also political purposes. At the heart of this visual narrative is the depiction of an Indic origin myth concerning poisons, exploring the themes of elixirs in the pursuit of immortality. The painting presented here steers an inquiry into the interconnectedness of medical ideas of poisoning within the broader notions of disease transmission. The images reveal Tibetan medical ideas of potency, interlinking the poisonous with the medicinal in intriguing ways: poisonous substances could also be used as antidotes to poisoning when properly processed, but they could also be “cast” to cause intentional poisoning. Through existing reproductions of these visuals, this paper explores and analyzes the dynamics between forms of poisoning and the antidotes used to treat poisoning. What understanding of poisoning and contagion can we draw from this almost four-hundred-year-old medical painting?

Keywords Tibetan medicine (Sowa Rigpa) – contagion – poisoning – medical iconography – *Four Tantras* (*Rgyud bzhi*)

Introduction

Recent discussions on the COVID-19 pandemic have brought questions on contagion to the forefront, also within the history of Asian medicines (HANSON 2022). This paper contributes to the relatively unexplored domain of disease transmission in Tibetan medicine (Sowa Rigpa). It does so by highlighting visual representations and unraveling the intricate layers of Tibetan perceptions surrounding “poisons” and “contagion.” The notion of “contagion” here refers to disease transmissibility in a broad sense, encompassing numerous activities that appear as crucial in Sowa Rigpa in the transmission of disease, for example touch, pollution, poisoning, animal bites, as well as miasmatic vapors.¹ The primary visual focus of this inquiry centers on one of the seventy-nine scroll paintings, known as *thangkas* (*thang kha*), a unique collection and the first and only comprehensive visual representation of medical knowledge in historical Tibet (GYATSO 2014: 199).

The original set of *thangkas* was prepared in Lhasa over a period of sixteen years, between 1687

and 1703. Work began while DESI SANGYÉ GYATSO (1653–1705), the regent of the Fifth Dalai Lama Ngawang Lozang Gyatso (1612–1682), wrote *The Blue Beryl* (*Vaiḍūrya sngon po*) medical commentary (SANGYÉ GYATSO 1982). Completed in 1688, it explains and elaborates the *Four Tantras* (*Rgyud bzhi*), a foundational Tibetan medical text in four parts largely compiled during the twelfth century (YUTOK YÖNTEN GÖNPO 1982). DESI SANGYÉ GYATSO initiated the painting of the seventy-nine *thangkas*, which visually encapsulate the structure and content of both works.

While the original *thangkas* have been lost, various reproductions from the early twentieth century have been published in the 1990s, providing a rich field for scholarly analysis (for example, AVEDON & MEYER 1998; JAMPA TRINLÉ *et al.* 2008 [1994]; PARFIONOVITCH *et al.* 1992). Researchers have analyzed several aspects of them over the years accentuating, for example, Tibetan anatomy and the subtle channels (GARRETT & ADAMS 2008; GERKE 2012, 2013; GYATSO 2015a; SABER-

NIG 2019), surgical instruments (MCGRATH forthcoming), embryology and gender (GARRETT 2008; GYATSO 2010–2011, 2015a; YOUNG 2011), as well as the structure of the various versions of the existing sets (ZHEN AND CAI 2019), together contributing historical, textual, and ethnographic insights to our knowledge of these medical paintings.² To date, JANET GYATSO (2015a) has written the most elaborate historical textual analysis of the paintings and their making. While her theoretical analysis remains contested, she analyzes many of the Buddhist medical interfaces of the images and how the *thangka* set is representative of the science and religion debate in Sowa Rigpa, which I discuss in the context of mercury processing in *Taming the Poisonous* (GERKE 2021: 134–35). An art historical analysis of the existing *thangka* sets is still awaited.

Tibetan ideas of poisons and poisoning are part of a more complex corpus of contagiousness ideas in Sowa Rigpa. The geographic location of historical Tibet and its exchange with its Asian neighbors led to a historical development of medical thinking that was highly heterogenic in nature. Textually, various chapters of the *Four Tantras* disclose Indian ayurvedic and/or early Tibetan providence (YANG GA 2010). Thus, it comes as no surprise that Sowa Rigpa discourses on infectious disease historically come from different sources and are spread across several chapters of the *Four Tantras* and the *Blue Beryl*.

Concepts akin to what we would now term “contagion” are found in the chapters on fevers, skin diseases caused by demons, the chapter on “pustule disease” or *drumné* (*'brum nad*, often translated as smallpox³), and other infectious diseases clustered under the Tibetan terms *rimné* (*rims nad*) and *nyenrim* (*gnyen rims*). Notably, visual representations of disease transmission appear in at least three of the seventy-nine *thangkas*. The Tibetan history of infectious diseases is complex and multilayered and has left different visual traces on these *thangkas*. Since their analysis would be extensive, I will only focus on one of them here in detail (*Thangka* 51).

GYATSO mentions this *thangka* only briefly in one article (2014: 215), where she highlights its expression of heterogeneity concerning the medical practices in Tibet in relation to India. This *thangka*

portrays an Indic origin myth involving the search for the elixir of immortality through the churning of the milky ocean from which poisonous substances emerge. It lists the substances that cause and treat poisoning, as well as modes of transmitting poisons. I previously analyzed this *thangka* in the context of the transformation of mercury into an elixir, emphasizing the essential message that poisons cannot only be transformed into elixirs, but can also be used to make antidotes to treat poisoning (GERKE 2021: 49). Here, I explore and analyze the visual dynamics between poisons and their antidotes. What kind of ideas of disease transmission emerge from individual images of this almost four-hundred-year-old medical painting? How does poisoning relate to disease transmission and what does this tell us about medical concepts of contagion in Tibet?

Why paint medical texts?

DOMINIQUE TOWNSEND (2021), in her examination of the monastic educational system at Mindröling Monastery in Tibet, highlights a distinctive feature of the Buddhist model of education. Unlike medieval European universities that excluded medicine from their seven “liberal arts” model of learning, the Buddhist approach included medicine as one of their “ten sciences” (*rig gnas bcu*) (TOWNSEND 2021: 165).

During the time these medical *thangkas* were crafted monastic education in Tibet was very comprehensive. It included medicine, grammar, dialectics, and Buddhist doctrine, poetics, composition, the study of synonyms, drama, astrology, as well as arts and crafts. *Thangka* painting was a craft in itself and played a significant role, with monasteries decorating their walls portraying Buddhist stories, symbols, and deities. While the idea of preparing a scroll painting of medical images was not entirely new in the seventeenth century, it represented an innovative endeavor. What makes these images even more unique in the larger Asian medical context is the absence of comparable pre-modern medical paintings or drawings in Ayurveda.⁴ Artists in China produced numerous medical drawings and diagrams (LO & BARRETT 2018), but none comparable to the comprehensive set of Tibetan medical *thangkas*.

The purpose behind preparing the seventy-nine *thangkas*, meticulously outlined by JANET GYATSO (2014; 2015a: 40–47) can be succinctly summarized. Primarily, they serve as educational illustrations of the *Four Tantras* and the *Blue Beryl*. Since the *Four Tantras* is a poetic work, partially memorized by medical students (even to this day), painting the content was chiefly a mnemonic method. The arrangement and sequence of images facilitates students to memorize the order and content of each chapter. DESI SANGYÉ GYATSO himself emphasized the efficacy of using illustrations as a pedagogical tool, stating that “pointing a finger” at the images would enhance the learning experience (GYATSO 2015a: 44).

However, at the same time the *thangkas* also represented the authority of the text itself involving the Tibetan state, which sponsored the project. They thus underline the political significance of a medical tradition during an important historical period, namely the rise of the Fifth Dalai Lama’s Ganden Podrang Government in Lhasa (GYATSO 2014: 200, 2015a; SCHAEFFER 2003). While the Desi was enthusiastic about the Mahayana ideal of helping others and taught himself the *Four Tantras*, his political vision, shaped by his long relationship with the Dalai Lama, aimed at the establishment of Buddhism as a state religion also through the field of medicine (GYATSO 2015a: 94–96). GYATSO argues that, beyond their political role, the scroll paintings also displayed “a distinctively medical perspective on Tibetan culture overall” (GYATSO 2014: 199), illustrating the absence of strict boundaries between religious and secular life in Tibetan Buddhist society at the time. They might have also been part of “merit publishing,” similar to what VIVIENNE LO describes in the context of Buddhist publishing in China (LO 2018: 13). This refers to a practice through which the sponsoring of publications would generate merit for the donor. In summary, the *thangka* set illustrates a unique creative and innovative endeavor of Tibetan medical art, steered by DESI SANGYÉ GYATSO himself, and fulfilling various purposes.

Creativity in the medical paintings

Buddhist *thangka* painting is known for its rigor and adherence to tradition, which could potentially be seen as lacking individuality and origi-

nal conception. However, its primary purpose is to ensure the continuity of religious authority and the authenticity of Tibetan art (JACKSON & JACKSON 1984: 42). Because it required artists to translate elaborate details from the chapters of the *Four Tantras* into visual imagery, a task previously unexplored by Tibetan artists, the medical paintings allowed for greater individuality and creative composition. JANET GYATSO (2015a: 23–39) specifies how the making of these medical *thangkas* diverged from the more typical Buddhist imagery. They opened an imagining of the medical world not only of *materia medica* and specific medical practices but also of the sociality of sick and healthy people along with the medical ethics concerning daily behavior. Sangyé Gyatso and his team of artists must have comprehensively thought about how to transport textual information into visual representations. While certain textual sections proved challenging to depict visually, others were translated word by word with intrinsic picturesque features, incorporating images of plants, animals, minerals, and people. It seems likely that the artists behind the poison *thangka* (Fig. 1), discussed below, drew inspiration from existing mythical stories of poisoning, extensive *materia medica*, and various symbolic representations from daily life to render intricate ideas of poisons and their cosmological origins from text to image.

A vedic myth on the origins of poisons and elixirs

In brief, the myth tells this story (summarized from PARFIONOVITCH *et al.* 1992: 117):

The gods (on the top left of Fig.1) and *asuras* (usually translated as demons or antigods; here on the top right) in their desire for immortality decide to cooperate. They want to obtain a vase containing the elixir of immortality that is lying at the bottom of the ocean. Mount Meru (top center) is used as a churning staff and the serpent Vāsuki as a churning rope. The serpent is wrapped around the mountain and pulled from one side by the gods and from the other side by the *asuras*. Brahmā presses down the mountain and Viṣṇu manifests as a turtle to support it from below. Thus, they churn the milky ocean for a very long time. In the process wonderful things emerge from the



Fig. 1 The poison thangka (Plate 51), depicting three chapters from the *Four Tantras*. For this article the images are reproduced from this scroll painting, which was created by the DHARMAPALA THANGKA CENTRE, School of Thangka Painting, Kathmandu (Nepal, www.thangka.de). This thangka was previously published under an open access license (DHARMAPALA THANGKA CENTRE 2019/CC-BY-SA 4.0 in GERKE 2021: 48).

ocean: the sun, the moon, a horse, an elephant, and a wish-fulfilling tree, Goddess Laxmi, and a gemstone. Most of these are taken by the gods and enjoyed in their abode as their common property (top left). A beautiful goddess of wine also appears – weaving an origin myth of wine into the story – but the wine can only be drunk by the gods.⁵

Then, a terrible-looking creature with yellow hair and fiery eyes emerges from the ocean (depicted at the center). It is Kālakūṭa or Halāhala, the manifestation of poison. It can only be subdued with the mantra syllable HUM, which Brahmā and the gods recite. Through the power of HUM, Halāhala's body is shattered and its pieces are dispersed around the world. An alternative account mentions that Viṣṇu swallows the body of Halāhala and falls unconscious, but Śiva comes to his rescue and swallows the poison. However, the poison obstructs his throat and his neck turns blue, hence he becomes known as the “blue-necked one” (Skt. *Nilakaṇṭha*, Tib. *mgrin pa sngon po*).

Eventually, the vase with the elixir of immortality emerges from the ocean, but is seized by Rāhu (an *asura* who has disguised himself as a god). Viṣṇu hurls a disk at him and decapitates him. As a consequence, some drops of the elixir fall on the ground and give rise to various medicinal herbs such as myrobalan, and garlic (which is made from the elixir mixed with Rāhu's blood).

The painting includes yet another version of the myth depicting Śiva spilling elixir across the earth, giving rise to substances that could serve as antidotes to poisoning. These, especially aconite, hold particular relevance for medical practitioners. From Halāhala itself the category of “actual poisons” (*dnogs dug*) emerges, exemplified by substances like black and yellow aconite. Additionally, “compounded poisons” (*sbyar dug*), designed to inflict harm, can be derived from various gems, metals, and minerals.

To sum up the story: both elixirs and poisons arise from a common source. Since they arise from the same source, poisons can be transformed into elixirs; and medicinal substances crafted from drops of the elixir, mixed with the blood of an *asura*, possess the unique ability to transform poisons into elixirs, but also to make antidotes to treat poisoning. Certain substances featured in the *thangka* serve dual roles, appearing both as poisons and as components of antidotes.

The prominence of the myth in the painting

The poison *thangka* illustrates the three chapters on poisoning (chapters 87–89 of the third section of the *Four Tantras*), with a particular emphasis on the poison myth from the Indian epic Mahābhārata. The painters here gave prominence to Hindu cosmology and drew the characters of the Vedic myth of the churning of the milky ocean, a well-known narrative found in various versions in the Mahābhārata and the Purāṇas. Multiple renditions of this myth exist in Tibetan medical and tantric literature (MCGRATH 2017: 308–31), which Desi Sangyé Gyatso must have been familiar with. Despite the brief mention of the myth in the *Blue Beryl* commentary and the *Four Tantras*, the *thangka* gives it central prominence. This aligns with the typical inclusion of Indian origin myths in tantric Buddhist teachings and the tendency in Tibetan iconography to position the deity at the center of the events. The primary figure, Halāhala is depicted in a style reminiscent of Tibetan *thangkas* portraying wrathful protectors. However, in this medical painting, Halāhala is not intended as a visual aid for meditative visualization practices.

Instead of conducting an iconometric analysis, my focus is on exploring the embeddedness of the myth within the medical knowledge surrounding the figure of Halāhala. I aim to raise questions about additional reasons, beyond the typical trope mentioned earlier, for why the poison myth assumes such a central position in depicting Tibetan medical perspectives of poisons and contagion. Since we cannot talk to the artists or Desi Sangyé Gyatso himself to find out their potential motives, my discussion remains speculative.

First, for the myth to be painted in such detail, it is likely that Sangyé Gyatso drew upon various sources. While the mythical land of Tanaduk (featured in Plate 1) is mentioned in Abhidharma cosmology (GYATSO 2015a: 158), the poison myth (Plate 51) also appears in the Purāṇas and in Tibetan tantric texts (for example, the Gāruḍa Tantra) with variations (MCGRATH 2017; SLOUBER 2017). Additionally, early commentaries on the *Four Tantras*, such as the *Eighteen Ancillary Branches* (*Cha lag bco brgyad*; YUTOK YÖNTEN GÖNPO 1999), which Sangyé Gyatso was familiar with, include reference to the poison myth. SANGYÉ GYATSO does not mention the poison myth specifically in

his own account of creating the *thangkas* (SANGYÉ GYATSO 2010: 338–45). But the fact that the *thangka* merges several versions of the Indic myth into one story says something about SANGYÉ GYATSO's storytelling choices and decision-making, warranting further research. SANGYÉ GYATSO, being both a politician and a physician-astrologer with training in Buddhist philosophy, although not an ordained monk, possessed the skills to combine diverse fields of knowledge, including art and painting, as is also evident from his patronage in these domains (CÜPPERS *et al.* 2012: 3–4).

Second, Tibetan medical scroll paintings, much like the associated texts, underscore the importance of understanding Buddhism and whatever came from the land of the Buddha itself – India. This emphasis on the source of medical and Buddhist knowledge is apparent in various ways in Tibetan medical texts, and in the medical *thangka* set it is notable in at least two paintings (Plates 1 and 51). For example, the first scroll painting of the set features the mythical land of Tanaduk with the Medicine Buddha at its center, combining ideas of the mandala with the cosmological and sacred geography of medicinal substances. It also illustrates the much-debated origin myth of the Medicine Buddha teaching in the *Four Tantras* (see GYATSO 2015a: 35–36, 149, 158). While the poison myth does not seem to have given rise to such contestations among Tibetan authors, its visual prominence pays homage to India as a source of medical knowledge, extending beyond the realm of Buddhism. This Vedic myth underscores the heterogenous nature of medical knowledge in Tibet and acknowledges it, which is a known trope in Tibetan medical writing (GYATSO 2014: 215; YOEELI-TLALIM 2021: 37; YANG GA 2010: 235–38).

Third, stories are not only good to think with but also good to paint with. They have plot, a cast of characters, and might lend themselves to produce more exciting imagery than lists of substances. While it might be argued that the figure of Halāhala itself was painted in a rather conventional style that one can also observe in other paintings of dharma protectors, the ways in which his figure is embedded in this poison-specific medical context was quite creatively done and offers interesting aspects for analysis.

We can see that the artists took great effort to depicting the details of the story's characters

(Brahmā, Rāhu, the gods and *asuras*, and the torn body parts of Halāhala in the milky ocean). However, the bowls of substances surrounding the story do not consistently exhibit the same level of detail. In some instances, though great care was taken, it would be difficult even to identify the substances based on their sketches. While this artistic focus may be justified from the artist's technical standpoint, it does not fully account for the substantial canvas space allotted to the myth. The *thangka* portrays thirty-six substances used in compounding poisons, all intricately connected with thin golden lines to parts of Halāhala's torn body pieces in the milky ocean. In practical terms, drawing linear connections between thirty-six substances and Halāhala necessitates representing the poison god in a central position.

Fourth, looking deeper into the narrative's content, an important element of hope arises from the poison myth. The fact that there is a remedy for poisoning which at the same time has elixir qualities and promises longevity if not immortality, might help ease fears concerning intentional poisoning – a persistent aspect of political rivalry in Tibet (CZAJA 2013: 86). The extensive list of antidotes and anti-poisoning formulas in the *Four Tantras* shows that poisoning was a genuine threat, and a physician had to know how to treat it (CZAJA 2019: 288).

The myth emphasizes that the strongest poisons can be the best elixirs, and that there is medical potential in the existence and usage of poisonous substances in medicine. The central message of the myth is: The more potent the poison the superior the elixir. It suggests that anything harmful can be turned into something beneficial through skillful means, may they be of ritual, tantric, or pharmacological nature. This combination reveals an immense potential for creating potent medicines through combining religious and medical methods, as exemplified in the consecration rituals of “accomplished medicines” (*sman grub*). Metaphorically speaking, the nectar-poison analogies of the *thangka* further underline the primary objective of Sangyé Gyatso's *thangka* project, a point also emphasized by SCHAEFFER (2003): Buddhism could be firmly established as a state religion, also through the field of medicine.

This combination of depicting the Indian myth, its medical theory of poisons, and their antidotes

also underscores a point made by JANET GYATSO (2015b) in her Aris Lecture: “It is the case, historically speaking, that Tibetan intellectuals tended to regard anything coming from India as authoritative and a sign of high culture...” Simultaneously, Tibetans acknowledged the value of certain great literary works from India, with GYATSO specifically referencing the Daṇḍin’s *Kāvyaḍarśa* – a classic work on poetics – as “theoretically sophisticated and interesting, quite beyond its coveted ‘Indian origins’”

Expanding on GYATSO’s observation, one might consider how Tibetans came to include Indian origin myths into their medical texts and paintings. While speculative, it could be that the Tibetan medical establishment, particularly around SANGYÉ GYATSO, found the narrative of poisons as potential elixirs through the tantric and medical transformations of substances intriguing for practical reasons – antidotes. This notion may have contributed to the myth’s visual prominence in this *thangka*.

Depicting the “casting of poisons”

Next, let us explore how the transmission of disease, here called “casting poison” (*dug bskur ba*), is depicted in this *thangka*. The term poison, in Tibetan called *duk* (*dug*), has a broad meaning beyond mere toxicity. It also denotes a substance that is difficult to digest. Even substances without *duk* can become *duk* for the body if consumed together, such as milk with radish. Therefore, *duk-dön* (*dug ’don*) the process of “removing the *duk*,” is an important part of Tibetan medicine-making or *menjor* (*sman sbyor*). It aims at rendering substances digestible and usable in multi-compounds, removing or transforming their *duk* and unlocking their medicinal potencies. One of my central research questions here is: How does the *thangka* portray themes of disease transmission and how are these related to notions of *duk*?

Tied to this analysis is also the well-known methodological question on retrospective disease identification: How to interpret a seventeenth century artifact depicting forms of disease transmission without reading our own understandings of “contagion” retrospectively into it? How can we understand the ideas conveyed in images painted in the seventeenth century that depict a

text written in the twelfth century, or even earlier? In the process of “reading” the images, I navigate between them and their textual descriptions, attempting to convey the visual message in context without retroactively identifying what is being transmitted. Unfortunately, we miss out on SANGYÉ GYATSO’s oral sources that informed the creation of the *thangkas* (GYATSO 2010–2011: 226).

The images reveal three visual domains related to aspects of “casting poisons”: (1) drawing the poisonous substances themselves (animals, metals, minerals, and herbs); (2) sketching five ways of transmitting *duk* through “poisonous air,” human touch, and activities related to hospitality; (3) illustrating the motivation for intentional poisoning. All of these domains exhibit creativity and ingenuity by the artists, who combined different ways of painting objects, human emotions, and the everyday human world, including a range of *materia medica*. In the following I analyze each of these three domains.

Poisonous substances

As mentioned earlier, the *thangka* depicts thirty-six substances used in compounding poisons. These substances are connected to Halāhala’s body parts through thin lines, indicating their origins in the manifestation of poisons. Since they derive from poisons, they can be used in compounding poisons, even though some of them are not considered to have *duk*, and most of them are known to have medicinal potency when properly processed. Among the thirty-six substances are plants (primarily various types of aconite, Fig. 2), metals (mercury, lead), mineral substances (sulfur, cinnabar) (Fig. 3), and meats (a list of animals is mentioned including scorpions, spiders, goats, dogs, horses, and so forth) (Fig.4).

The twelve precious metals and minerals are portrayed in bowls (Fig. 3 partially identifiable by their shape (e.g., limestone has the form of standing crystals) or color (e.g. white for limestone, red for cinnabar, yellow for sulfur). However, most of them lack sufficient detail to be recognized without their captions. Lead (*zha nye*) and iron (*lcags*) are painted blue in unusual shapes.⁶ GYATSO (2015a: 56) observes that, “While there can be little doubt that the Desi and his team obtained some real examples from which to draw, we are not sure

how much of the set was actually executed with live models in sight.” While we do not have access to the Desi’s original set of this *thangka* from the seventeenth century to make a definite statement, I note that when compared to plants, animals, and humans, the depictions of metals and minerals in this *thangka* are often vague, and some substances (e.g., limestone and cinnabar) seem to adhere in shape more to the classical *thangka* painting motifs of drawing rocks (JACKSON & JACKSON 1984: 158) than to live models.

Meats are important in this section and are depicted in the form of live animals (Fig. 4a & b), which provide the meat for intentionally compounded poisons and are also sources of naturally occurring poisons such as snake venom. Poisons are derived from animal blood, bile, hair, and bones. Painting the animals from which these substances are sourced makes them easier to identify.⁷ Many of the animals depicted in the section of compounded poisons (Fig. 4a) reappear three rows further below in the images referring to chapter 89 on naturally occurring poisons (Fig. 4b): a tiger, a scorpion, a worm, and a rabid dog, symbolized by a red collar. A patient suffering from “dog poisoning” or rabies (*khyi dug*) is painted with yellowish skin (Fig. 4b, bottom right).

This section also provides practical guidance on meat poisoning, depicted in everyday activities such as handling contaminated meat (Fig. 5) and



Fig. 3 The precious metals and minerals used in compounding poisons (from top to bottom, left to right): precious metals: gold (*gser*), copper (*zangs*), mercury (*dnngul chu*), bronze (*khar*), iron (*lcags*), lead (*zha nye*); minerals: “frog-back” iron hydroxide ore (*sbal rgyab*), zinc (*ti tsha*), limestone (*cong zhi*), cinnabar (*mtshal*), sulfur (*mu zi*), and galenite (*pha wang*) (Identifications follow PARFIONOVITCH et al. 1992: 273).

poisoning through the consumption of incompatible foods (Fig. 6).

Ways of transmitting and contracting *duk*

The *Four Tantras* list five ways through which *duk* can be transmitted, ranging from practical hygiene to gendered ideas of pollution (see Fig. 7 and 8). Accordingly, *duk* can be transmitted: 1) by sunrays through sight (*mthong ba nyi ma'i zer la bskur ba*); 2) by wind filled with poisonous smoke (*dur rlung gi rdzir bskur ba*), for example, from funeral rites; 3) through inhaling the vapor of the earth where one is accustomed to tread (*'goms pa'i sa'i rlang la bskur ba*), resembled by blue, red, orange, and yellow-colored rays emerging as round and straight shapes from three yellow steps; 4) by touch through oil (massage) or other contacts (*reg pa'i snum sogs kyi rtar bskur ba*), referring to sitting on contaminated cushions/seats (*gdan*), symbolized by a carpet, and having contact with women



Fig. 2 The poisonous plants depicted on the thangka as ingredients of compounded poisons are black and yellow aconite (*btsan dug*), datura (*thang phrom*), and madar grass (*bsi dug*) (Identifications follow PARFIONOVITCH et al. 1992: 273).

who carry impurities; and 5) internally through diet (*khong par zad la bskur ba*), sharing alcohol (*chang*), plates of food (*sder ma*), and cups (*phor ba*).

Figure 7 depicts colorful thin, straight, and curly contaminated rays coming down from a bright orange sun (left). This image refers to the power of magic (*mthu nus pa*) by which the practitioner transmits *duk* through sun rays that the

victim looks at. The white-bluish smoke arising from a strong red fire (center) and green-shaded wind (right) ornately depict the transmission of a poisonous smoke. Here, the artists made use of known styles from landscape *thangka* painting, such as the sun, flames, and clouds (JACKSON & JACKSON 1984: 154–60). We also find this style on other medical *thangkas* depicting the humoral wind (for example, Plate 44).



Fig. 4a A list of animals that provide substances for compounding poisons.



Fig. 4b Some of the same animals are listed as causing poisoning in humans.



Fig. 5 Visual depiction of meat poisoning. Meat might be contaminated by a butcher’s blood (left). Eating a calf taken from a dead animal’s body might cause meat poisoning (right).



Fig. 6 Examples of food incompatibilities (from left to right) from Chapter 88: consuming curd (*zho*) with wine (*chang*), frying mushrooms in mustard oil (*ser sha yungs mar brngos pa*), and eating chicken with curd or fresh milk (*khyim bya’i sha zho ’o rlon pa*).



Fig. 7 Transmitting poisons through sunrays (left), and through wind filled with poisonous smoke (center and right).

In Figure 8, poisonous vapors (*slangs*) are sketched in round circular forms, emanating from a staircase, embellishing a woman's belly, circulating on a carpet, or hovering over a red jug of barley beer. The artists employed a combination of bright yellow, green, blue, red, and orange hues, along with round shapes in spiraling circles to visually represent what we might term miasmas⁸ or noxious air, while also including social layers of pollution. The woman is naked with long, curly hair, distinct nipples, and a spiraling miasmatic sign on her lower belly, signifying impurities related to menses and sexuality. This image should be interpreted within existing analyses of misogynistic depictions of female bodies in medical *thangkas* (GYATSO 2010–2011, 2015a), where impurities in women parallel their lower status in society.

During my ethnographic research project on mercury processing (GERKE 2021), I had the opportunity to question contemporary Tibetan physicians in India and Nepal on the five ways of transmitting poison shown in this *thangka*. The responses varied. Some delegate such harming activities to the distant past, acknowledging that sending poison through sunrays required special skills, which people today do not possess. Others discuss this section while attributing great wisdom to their ancient texts that predict air and environmental pollution, which today they claim to treat with the antidotes and remedies already outlined in the *Four Tantras*. Still others offer present-day interpretations of harmful sunrays. The Tibetan physicians TIDWELL & GYAMTSON (2021: 110) note, “Light radiation relates to a subset of virulent infections in which sunlight radiation may play a significant disease progression role. For example, in Herpes simplex virus, sunlight is a potent stimulus for reactivation or recurrent flare-ups and extended exposure in direct sunlight may also induce immunosuppression.” While these examples raise questions of retrospective disease identification, they also demonstrate innovative ways of Sowa Rigpa practitioners interpreting the concept of “casting poison” from contemporary perspectives of biomedicine, environmental pollution, and radiation.



Fig. 8 Transmitting poisons through inhaling the vapor of the earth where one treads (left), or by touch, such as sitting on seats (center top) and having (sexual) contact with women (center) who carry impurities. Internally, *duk* is transmitted through diet, sharing wine (the red round flask in front), plates filled with food (top right and bottom right), and drinking vessels (middle right).

A question of motivation: intentional poisoning

Intentional poisoning appears to have been a concern in Tibet, since the first of the three chapters on poisons elaborates on “compounded poisons” or *jarduk* (*sbyar dug*). *Jarduk* are toxic substances that are intentionally compounded and used to harm others. We need to understand the complex socio-political contexts in which poison practices were employed as political tools, and specialists such as physicians or Buddhist lamas had to treat them. Compendia by Tibetan Buddhist teachers often include protection rituals and mantras to counteract poisoning (for example, KONGTRUL & BARRON 2003: 523). Diverse poison cultures exist in Tibetan societies, some of which may not be explicitly mentioned in medical texts. Ethnographic studies in Eastern Tibet (DA COL 2012) discuss practices of poisoning through hospitality to exploit the economic fortune of the victim. CHARLES RAMBLE & NALJOR TSERING (2020) recently analyzed a range of poisoning practices in the Tibetan Himalayan regions, in an effort to place and contextualize a rare manuscript on toxicology found in Mustang. Notably, the existing fragments of this manuscript closely relate to the poison chapters in the *Four Tantras*, discussed here, suggesting the popularity or more wide-spread use of Tibetan medical knowledge on poisoning across the Himalayas.

To continue, chapter 87 in the *Four Tantras* mentions emotional reasons for intentionally ap-

plying poison. The artists faced the challenge of depicting human motivations to become poisoners as illustrated in Figure 9. Through a combination of text, symbols, and imagery, the intentions unfold: A person, half-naked and exuding hatred (*zhe sdang*) is portrayed next to a snake representing both hate and the poison itself (left); another individual driven by an inferiority complex (*ster rgyu mtho dgos*; center right) is set apart from others by a bare upper body and short hair. The victim suffering from poisoning (right) is depicted with yellowish skin, with his head tilted down and hair standing up.

In summary, the images analyzed in this section illuminate the narrative aspects of everyday experiences in Tibetan cultural life, specifically related to poisoning. These experiences involve both visible and invisible forms of *duk*, which are either intentionally cast or encountered unintentionally in daily interactions with air, animals, food, people, and places. Ideas of “contamination” emerge as a means of transmitting *duk* that can destabilize life and health. Substances may become toxic or indigestible through compounding, sharing, social interactions, or carelessness. Animals, plants, minerals, and metals can cause poisoning but also provide substances to counteract poisoning. The depicted transmission of *duk* suggests that poisons are inherent in people’s lives and should be understood by physicians to effectively treat various forms of poisoning.

Conclusion

In conclusion, I want to highlight the idea of the antidote, known as “opposite” or *nyenpo* (*gnyen po*) in Tibetan, representing the process of “neutralizing poison” or *dukjom* (*dug ’joms*) in a Tibetan medical context. The nature of poisons and their antidotes reveals Tibetan medical ideas of potency, intricately linking the poisonous with the medicinal: poisonous substances can serve as antidotes to poisoning when appropriately processed. The discourse on antidotes and elixirs emerges as an important element in understanding the art of medicine-making, where numerous substances have to undergo a *dukdön* process to transform the *duk* into something digestible and beneficial – medicine or *men* (*smän*). Notable examples from the *thangka* include various types of aconite, high-

ly poisonous roots with the capacity to act as both a poison and a treatment for disease. This poison-medicine spectrum also translates into the ways in which certain Tibetan formulas are compounded (GERKE 2021; VAN DER VALK 2019).

Themes of shared identities between poisons and their antidotes take us back to the myth: both poisons and the substances used to compound them, as well as their antidotes, originate from the same milky ocean of existence. It is a question of processing and transformation skills whether a poison, an elixir, or an antidote emerge. It takes a lot of churning of milk to make butter. Likewise, it takes a lot of skilled processing to turn poisonous



Fig. 9 Sketches of human motivations to become poisoners (left and center right) and a patient suffering from poisoning (right), making use of symbolism.

substances into beneficial medicines. The myth itself does not discuss “contagion” or transmission of disease, but offers the medical potential encapsulated in the duality of the nectar-poison spectrum – the existence of an antidote. In this sense, the *thangka* fulfills its educational purpose by visually explaining this fundamental idea of Tibetan medical toxicology.

Generally, we can conclude that Tibetans conceptualized disease transmission in part as poison-related. The poison *thangka* reveals very specific ideas of disease transmission clustered as “casting poisons.” This transmission can occur accidentally or intentionally. The poison *thangka* has a strong focus on substances and individual disease transmission. It would be valuable to compare this emphasis with the ways disease transmission is depicted in other chapters and *thangkas*, for example the *rimné* chapters on fevers, which deal with widespread and virulent infectious disease,⁹ or images of patients with “pustule disease” or *drumné* and other skin diseases (SAB-

ERNIG 2022). These *thangkas* and related texts reveal different facets of contagiousness.

In sum, the ideas surrounding disease transmission and the casting of poisons in the poison chapters and related images appear to be more connected to daily experiences rather than to the poison myth. While the origin myth traces back to India, the other images depict practical day-to-day scenes from Tibet. Culturally familiar encounters with poison affliction provide insight into every-day realities reflecting a distinctive medical orientation, which GYATSO calls “medical mentality” (GYATSO 2015a, 16). We saw visual advice on avoiding meat and other food poisoning (not consuming old dead animals or incompatible foods), refraining from sharing plates, and so forth. These indicate an awareness of potential health risks. The images highlight toxicological knowledge about poisonous bites, stings of animals, dog bites, and the naturally occurring poisons in certain plants. Embedding this knowledge in the narrative of a myth offers broader explanations and a set cosmology that explains why there are poisons and elixirs in this world in the first place. The images also point to existing knowledge of substances that were used to mix poisons intentionally, which was probably widespread across the Himalayan region as attested by the Mustang manuscript fragments on poisoning analyzed by RAMBLE & TSERING (2020) and other studies on poison practices in the Tibetan world (for example, DA COL 2012). Unlike in South Asia where local knowledge of poisoning steered different debates in their encounters with colonialism (ARNOLD 2016), in culturally Tibetan areas, this knowledge survived in fractured manuscripts, classical medical texts, medical paintings, and informs Sowa Rigpa medical practice to this day. As such it is an example of how toxicology is critical to the study of medicine, also in classical Asian medical traditions such as Sowa Rigpa.

While the modes of transmission (being bitten by animals, touching contaminated things, eating incompatible foods) are clearly depicted in the *thangka*, does this reveal an underlying theory of contagion? Questions about contagion theories in Asian medicines have been explored by historians, as seen in the edited volume *Contagion* (CONRAD & WUJASTYK 2000). Aligned with several authors in this volume, I would argue that even if we

can decipher some visual metaphors illustrating the casting of *duk* through “poisonous smoke” (*dur lung*) or “earth vapor” (*sa’i rlang*) as forms of disease transmission, it does not necessarily imply a distinct and separate entity akin to an external “pathogen” being transmitted. In other chapters of the *Four Tantras*, the vapor appears as “mouth vapor” or *kalang* (*kha rlang*), considered to be expelled by demons (*gnyan*) and causing a variety of widespread diseases or *rimné*. In the poison *thangka*, the poisonous vapor – often translated as *miasma* – seems more interwoven into the fabric of being part of the world, rather than defining an external “pathogen.” Thus, the *thangka* reveals a range of ideas on disease transmission. Notions of “miasma” and “contagion” passed on through proximity or touch do not appear as mutually exclusive ideas. Overall, these English terms seem limited in encompassing the ethical and social dimensions of “casting poisons” depicted in these paintings.

I conclude, based on the preliminary analysis of this Tibetan scroll painting, that Tibetan medical textual and visual depictions of poisons and poisoning of the thirteenth to seventeenth centuries cannot be reduced to modern ideas of a pathogen transmission. Disease transmission was conceptualized on broader and multi-layered levels, encompassing the exchange of virulent “poisonous air” between non-humans, the environment, and humans, involving the effects of environmental disruptions of spiritual abodes on human health. It also involved accidental or intentional acts of “casting of poisons.” This led to a set of disease categories clustered under “poisoning” or *dukné*, which included conditions like “dog poison” (*khyi dug*; probably rabies), food poisoning (*gyur dug gyi nad*), and forms of toxicity resulting from ingesting compounded poisons, contaminated or incompatible foods. The specific nature of the *duk* transmitted in each case is not addressed in the poison *thangka*, but could be further understood within the broader medical contexts of humoral physiology described in other chapters. Additionally, the ideas concerning which substance could counteract *duk* also constituted a diverse *materia medica* of animal, mineral, metal, precious stones, and herbal origins utilized in the making of “medicines neutralizing poisons” or *dukjom kyi men* (*dug ’joms kyi sman*). *Dukjom* in

itself should also be understood as a specific category of potency, describing a substance's potential to become an antidote to poisoning when appropriately processed.

Taken together, we see that a comprehensive knowledge of various aspects of toxicology existed in seventeenth century Tibet. It was colorfully illustrated by artists in the medical *thangkas*, by incorporating existing *materia medica* and everyday life experiences. My findings also speak to the broader recognition of the diverse poison/medicine spectrum described by historians across Asia, spanning from medieval to colonial times, addressing the importance of poisons as traded substances and antidotes, and poisoning as a cultural, often subaltern practice (see, for example, ARNOLD 2016; LIU 2021). While the *thangka* images are fixed in time on canvas, they also present material for comparative analysis in terms of larger trans-cultural narratives of disease and poison transmission. Additionally, they offer insights into the ambiguity of artisanal practices involving the compounding of poisons and contribute to the overall discourse on poisons as medicines.

Further research on the history of infectious disease in Sowa Rigpa should acknowledge this complex, multi-layered nature of disease transmission, challenging neat alignment with modern perspectives of pathogen-based contagion. The point to take home is that toxicity in Sowa Rigpa is part of a larger contagion complex and has multifaceted socio-political, gendered, and historical dimensions. The intricacies at hand dealing with text and imagery of past notions of disease transmission not only conflate concepts of poisoning, their antidotes, and the ethics of casting poisons, but also reveal an embeddedness in socio-historical dimensions of illness severity and the suffering inflicted upon individuals and entire communities.

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Notes

- 1 See the Introduction in CONRAD & WUJASTYK 2000 for a discussion on "contagion" in Asian medical contexts.
- 2 For a brief essay on a Tibetan medical exhibition, including *thangkas*, at the Rubin Museum of Art, New York, see HOFER (2023), and for the extensive exhibition catalogue see HOFER (2014).
- 3 SANGYÉ GYATSO himself received the transmission of a text titled *Experience of Treating Black Pustules through Mantras* ('*brum nag snags bcos nyams yig*), probably referring to smallpox, which he included in the upper cartouche of Plate 9 of the paintings (DORJE 1992: 15). On the history of smallpox in Tibet see YONGDAN 2016, 2021.
- 4 Email communication DOMINIK WUJASTYK, February 2, 2023.
- 5 The term *asuras* means "those unable to drink wine" or "those without the wine goddess" (PARFIONOVITCH *et al.* 1992: 117).
- 6 We do not know if the original version of this painting also depicts these metals in blue. The *thangka* painted by contemporary artists (for example, in AVEDON & MEYER 1998) or by the Dharmapala Thangka Centre (www.thangka.de) depict iron and lead in blue; older *thangka* replications used whitish-grey bluish colors (for example, JAMPA TRINLÉ *et al.* 2008 [1994]: 381, 384). JANET GYATSO (2010–2011: 220) notes that "it seems the original iconography was so expressive that the various copies continue to retain a freshness and human liveliness that approaches that which exudes from the earliest versions."
- 7 Compare with JANET GYATSO'S observations on the painting of live animals in the *thangkas* (2015a, 26–27).
- 8 Miasma is a polysemous term widely used for various types of disease-causing vaporous emanations associated with pollution, atmospheric changes, smoke, and foul smells.
- 9 WILLIAM MCGRATH is currently researching these chapters in detail as part of the FWF-funded project "Pandemic Narratives of Tibet and the Himalayas" at the University of Vienna.

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“Being Cultured”, Changing Culture

Public Health Messaging in COVID-Era Ulaanbaatar

ELIZABETH TURK

Abstract As poetic and political, images mobilized by public health campaigns are often dense with meaning and associations, even as they make certain assumptions about the good, virtuous, natural, and right. This article explores the assumptions about “being cultured” that underlie the “Let’s Make the City Cultured” campaign and related public health messaging in Ulaanbaatar, Mongolia’s capital city. In the image-slogan complexes mobilized by such campaigns, “being cultured” (*soyoltoi*), healthy (*erүүл*), and clean (*tsever*) is linked to curbing specific behaviors such as urinating and spitting in public, which took on new urgency in health-related discourses during the COVID-19 pandemic. As a concept that retains the legacy of meanings and associations in connection with state socialist era values, “being cultured” has been used in different yet connected ways across the 20th and 21st centuries to disseminate hegemonic messages. Drawing on the “Let’s Make the City Cultured” and related ideological public health campaigns, this article explores discursive efforts to generate a subject of the state that espouses bourgeois values.

Keywords political economy – ideological state apparatus – exemplars – postsocialism – propaganda

Introduction

Having returned to Ulaanbaatar in November 2021 after a protracted, pandemic-related absence, I first noticed visible features of the city that had changed: ostentatious displays of wealth exemplified in expensive sedans and SUVs, new luxury grocery stores and shopping malls, specifically crafted outdoor spaces in which to spend time with friends and family, as well as public signage designed to inspire ‘selfie’ moments. The presence of health-related messaging was ubiquitous, both in public spaces and privately-owned establishments, such as “wear a mask!,” “keep your distance,” and “stay home,” intended to prevent spread of COVID-19 infection, and much like signage in the UK where I had come from. Walking past the former Trade and Development Bank headquarters, where Little Ring Road meets Tourist Street, I noticed the once-stately bank had disappeared and now a large paneled fence surrounding the area, as the prime real estate was undergoing conversion likely to become a mall or high-rise apartments, similar to the Max Towers just behind it. On one of the fence panels I noticed

a three-part image display of a red circle-backslash symbol (typical of ‘forbidden’ signage) with the silhouette of person urinating, spitting, and littering inside each (see Figs. 1 & 2). Below the images was written: “Let’s create a trash-free, clean and civilized environment.” These images belonged to the “Let’s Make the City Cultured”



Fig. 1 Adjacent sign on a construction panel in central Ulaanbaatar. Photographs by author.



Fig. Adjacent sign on a construction panel in central Ulaanbaatar. Photographs by author.

(*Khot Soyoltoi Bolgoy*) campaign, sponsored by the Governor¹ of Ulaanbaatar City (Ulaanbaatar Khotiin Zakhiragch) beginning in 2019. The green and red lettering of the campaign's title and the ambiguous placement of words is a play on language, and so the slogan also reads "A Cultured City is Lovely" (*Soyoltoi Khot bol Goy*). In the image-slogan complexes presented by the "Let's Make the City Cultured" and other related campaigns that visibly populated public and private Ulaanbaatar spaces in 2021, "being cultured" (*soyoltoi*), healthy (*erüül*), and clean (*tsever*) were linked to curbing specific behaviors such as urinating, defecating, and spitting in public, which has taken on new urgency in health-related discourses during the COVID-19 era. In public culture, Ulaanbaatar – Mongolia's capital city and home to over half of the country's population – is often considered dirty, polluted, and congested in juxtaposition to the clean, healthful, wide-open spaces of the countryside. In contrast to the 'traditional' ways of countryside living, Ulaanbaatar is considered the modern nucleus of the country in vernacular thought, and associated with being cosmopolitan, forward-looking and trendy, being educated and receiving an education, the digital and technological, and so on. At the same time, important demographic shifts have taken place over the past few decades, with migration into Ulaanbaatar from the countryside and migration out of Mongolia from Ulaanbaatar, salient trends. The population of the city has nearly doubled since 1990, during which time the coun-

try moved from state socialist government and a centralized economy to multiparty parliamentary system and marketized economy. While important differences exist between countryside and urban economic activities and rhythms of daily and seasonal life, access to information, national and international news, and connection to others via internet and 4G is not one of them. Apart from the obvious geographical point, in many ways countryside and city people resist mapping onto two distinctive "communities" (and less appropriate still discrete classes or "ethnic" groups), as families are often split between rural and urban dwellings and a steady flow of goods, people, and cash takes place in between. The differences between the countryside and city people in public thought is largely attributed to divergent lifestyles associated with occupational realities, with portions of the population in both groups controlling and regulating the means of production.

This article explores how the "Let's Make the City Cultured" campaign and related public health messaging rely on normative ideas about what it means to 'be cultured' even as they seek to reform public culture. As the notion of "being civilized" or "cultured" (*soyoltoi*) retains bourgeoisie connotations in Mongolia, standing for cultivated taste and embracing the sophisticated, educated and "the arts," the normative assumptions about "cultured" behavior reveal underlying classist values that resonate more generally with the influence that celebrities, athletes, influencers on social media, and other publicly visible figures are considered to have in contemporary public life. However, the value of "being cultured" is far from new, instead having been shaped and circulated in connection with ideas about education, public order, and health and hygiene from the mid-20th century.

As a concept that retains the legacy of former meanings and associations, but also migrates, appropriating new associations,² 'being cultured' has been mobilized in different yet connected ways across the 20th and 21st centuries in Mongolia to disseminate hegemonic messages. Such dominant, "top-down" messaging disseminated in the "Let's Make the City Cultured" campaign brings to mind French Marxist structuralist LOUIS ALTHUSSER's scholarship in *Lenin and Philosophy and other Essays* (1971), as one of many possible

forms that an ideological state apparatus (ISA) can take, the transmission and dissemination of which reinforce the control of the dominant class. Generally considered to further ideas about Gramscian hegemony and Marxist ideology,³ one key point of ALTHUSSER’s model is to illuminate the ways in which ISAs reproduce the relations of production which, in the capitalist mode of production, are exploitative (ibid. 146). He comes to this conclusion by expanding upon the Marxist concept of the state apparatus; as opposed to political revolutions that affect the possession of state power, state apparatuses can survive without being affected or modified, ALTHUSSER (ibid. 134) tells us. He distinguishes between two kinds of state apparatuses: repressive, constituting the government, administration, army, police, courts, and prison, which function primarily by violence; and ideological, such as churches, political parties, trade unions, families, schools, the media, and so on, which function primarily by ideology (ibid. 138). Discussed in the following section, for ALTHUSSER, human beings become subjected to ideology and emerge as particular kinds of subjects through a structural and totalizing process called interpellation. He is largely preoccupied with schools as the dominant form of ideological state apparatus in a mature capitalist social formation, as it reproduces relations of production by inculcating, en masse, the ideology of the ruling class, replacing the church as the previously-dominant ISA in global north contexts.

Although ALTHUSSER’s writings has been variably received and critiqued over the years, especially for the absence of individual agency proposed therein,⁴ I am interested in reading “Let’s Make the City Cultured” and related public health messaging in COVID-era Ulaanbaatar alongside his notion of ISAs for two reasons, both relating to the analytic purchase the latter lends the former. First, I am interested in what ‘being cultured’ as social value mobilized by these campaigns tells us about how social change is imagined to take place, by those with the means, power and authority to circulate such messages. Because ideological state apparatuses can, in some ways, endure political revolutions, they tell us something about the legacy or endurance of social values across disparate political regimes. Read in this light, and with respect to normative ideas about citizen’s du-

ties, health, and being educated, “post-socialism” might remain useful, even if the analytic purchase is localized to specific social phenomena and intended to highlight the durances (instead of ruptures) across state socialist to ex-socialist transitions. This is then in constructive dialogue with claims that post-socialism is a ‘vanishing object’ (BOYER & YURCHAK 2008: 9; MÜLLER 2019) that would likely disappear with time (HUMPHREY 2001: 13). My aim is then not to examine the extent to which “Let’s Make the City Cultured” and related ideological campaigns were actually successful in changing thought or behavior or, in Althusserian terms, the extent to which Mongolians were interpellated. I am more interested in how ideological subjectification is imagined to take place, by those who control such messaging (even if not stated or understood exactly as such by the institutions in power).

Second, I am interested in exploring Mongolian public health messaging alongside ALTHUSSER’s scholarship for the insight such enquiry provides by way of class-making as discursive process. Though he does not directly speak at length about class relations in his chapter on ‘Ideology and Ideological State Apparatuses’ (1971: 121-173), ALTHUSSER mentions that ‘the Ideological State Apparatus may be not only the stake, but also the site of class struggle, and often of bitter forms of class struggle’ (italics in original) (ibid. 140). In a footnote, he qualifies that MARX distinguishes between the material transformation of the economic conditions of production and transformation in terms of ideological forms (e.g. legal, political, philosophic, and so on) in which men become conscious of this conflict and fight it out. ALTHUSSER reads MARX as saying that class struggle is thus expressed and exercised in ideological forms, inclusive of ISAs. But class struggle also extends far beyond such ideological forms (rooted, as it is, in relations of production), and for that reason “the struggle of the exploited classes may also be exercised in the forms of the ISAs, and thus turn the weapon of ideology against the classes in power.” ISAs then reveal something about class relations, even as class has been shown in recent updates to Marxist theory not to be a static structural category ‘out there’, but rather in co-constitutive relationship with social and cultural processes and projects of self-making (e.g. YANAGISAKO

2002: 70-109). I am interested then in the kinds of discursive class-making assertions “Let’s Make the City Cultured” and related public health messages render possible, however fleetingly, partial, and incomplete, and however variously received by different publics, whether disputed, rejected, or allowed to exist in qualified ways.

COVID-era public health messaging in Ulaanbaatar linking “cultured” behavior to public safety and citizen’s duty retains some of the meanings and associations established during the state socialist period, while taking on contemporary values in Mongolia’s “age of the market” (*zakh zeeliin üyed*) or “business age” (*biznisiin üyed*), as the current times are commonly referred, marked by salient social media presence and trend for campaigns aimed at changing individual behavior to be hosted on social media platforms, and disseminated with the help of influencers. As discussed more below, the “Let’s Make the City Cultured” campaign and associated public health messaging links “cultured” behavior with the refined, well-educated, considerate, social norm- and law-abiding conduct of the city, with derogatory classist connotations for non-city dwellers, be they intended or unintended. However, distinctions between “cultured” and “uncultured” behavior resist mapping onto countryside and urban dwellers as two distinctive classes, even as the social effects of urbanization and migration from countryside to city has been well documented (BRUUN & NARANGO 2006; CHARLIER 2020).

As I will argue, the “Let’s Make the City Cultured” campaign mobilizes its central concept by discursively naturalizing ‘being cultured’ as a universal value to all Mongolians, but to which city dwellers have better access, while also trying to shape “the city” as field. Here I draw on BOURDIEU’S (2013[1977]) notion of field, as a kind of social space amongst many in which interactions take place. As part of a series of concepts integral to BOURDIEU’S theory of social class and its reproduction which also includes habitus and capital, fields can be social realms such as politics or education, professional spheres such as medicine, or specific institutions such as a university. A set of tacit rules govern interactions within a particular field, and the better one has or develops a “feel for the game,” as BOURDIEU puts it, the more capital

(cultural, social, economic, symbolic) one is able to attain. For the purposes of city (*khot*) as field, it is the unwritten set of rules that the “Let’s Make the City Cultured” campaign sets out to describe (and in so doing, prescribe) that interests me. Crucially, the field of “the city” extends into online spaces like Twitter, Instagram, Facebook, and YouTube, the unique affordances of which amplify the reach of campaign messaging and provide digital spaces for ‘grassroots’ exemplar-ship to spread.

“Improving the introduction of the city’s Culture”: The prescription of rural-urban divisions

Whether traveling by bus, car, or on foot, public health messaging was nearly ubiquitous in COVID-era Ulaanbaatar. Depicted in various locations around the city but concentrated in the centre, highly digitalized, futuristic sets of large paneled images from this campaign line construction walls, behind which renovations or new builds take place. Such images depict clean-lined skyscrapers reaching into a clear, light blue sky; other panels feature a typical “green” urban space: wind turbines, trees and suburban-like homes dot the background, while shapes of faceless people enjoy the outdoors in the foreground: a woman pushing a stroller, a child riding their scooter. Short, punchy phrases are written across each, such as: “a clean city from us” and “trash-free environment – healthy life.” Details hinting at what a “cultured city” might entail are especially visible in certain forms of the signage; lettering includes two, Facebook-like “thumbs up” that form the diaeresis above the “e” of *roë*, which in turn doubles as the adjective “lovely” and also as the ending of the verb *bolokh* “to become, to make” rendering it first person plural imperative – *bolzoë* – meaning “let’s make” (see Fig 3). A broken up, straight line resembles dotted central road lines on the “t” of “city,” connoting following driving laws, while the bowtie forming the diaeresis of *coëñ* (meaning culture) illustrates the perceived social value of being refined and fashionably well-presented in public life. A number of hashtags in Mongolian language not only remind that the campaign has a vibrant social media presence online, but also further elucidate the Governor of Ulaanbaatar’s message: #PublicSpace, #ServiceSpace, #Traffic,

#PublicTransport and #OnlineEnvironment. Next to #TogetherLet’sChange is the *garuda*, a Buddhist mythical bird and symbol of Ulaanbaatar city, signifying the Governor’s official endorsement.

The Governor’s office is joined by several other organizations in such messaging, including some transnational organizations such as World Vision,



Fig. 3 “Let’s Make the City Cultured” sign near Monnis Tower, central Ulaanbaatar. Photography by author.

the World Health Organization (WHO), UNICEF, and USAID. These signs tend to link behavior such as spitting in public to preventing the spread of COVID-19 and infectious diseases more generally. The WHO has published signage incorporating spitting into health-related behavior to be avoided along with “close contact [with others] when you are experiencing cough and fever.” Sponsored by the Ministry of Health, the National Centre for Public Health, and the Asian Development Bank, a poster displayed inside a central indoor market called *Bömbögör* appeals to potential spitters by encouraging them to consider how their behavior might contribute to the spread of illnesses like COVID-19 (see Fig. 4). It also illustrates where such illicit behavior is considered to take place (e.g. the bus stop) and perpetrated by whom: e.g. a middle-aged man, appearing more disheveled than the similarly-aged man and woman standing behind him. The title reads, “Do not openly ‘throw’ (*khayakh*) your snot or phlegm” and in smaller text below: “Attention: do not put yourself or others at risk by spitting on the street, as this poses a risk of spreading infectious diseases.” Other signs appear more handcrafted. This one, displayed in Fig. 5, is written on a sheet of A4 paper, protected by a



Fig 4 COVID-era public health poster, sponsored by the Asian Development Bank, the National Centre for Public Health, and the Ministry of Health. Photography by author.

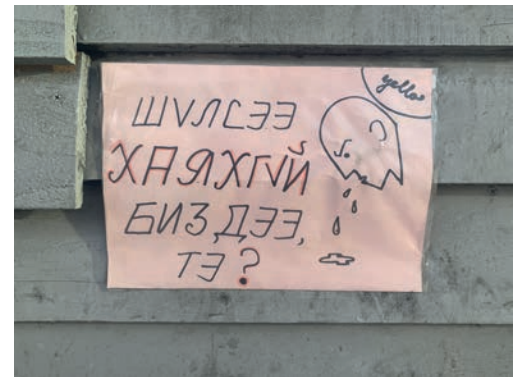


Fig. 5 Hand-made sign posted near Natsagdorj Library, Seoul Street. Photography by author.

clear plastic sleeve and taped to a building along the city’s central Seoul Street. It reads: “You won’t throw’ your saliva, right?”

Collectively, visual public health messaging belonging to the “Let’s Make the City Cultured” and related campaigns aims to change public health-related behavior, relying on a few different strategies. Along with propagandistic appeals to join the “culturedness” of the city, the Ulaanbaatar city’s Governor’s office fines for spitting and smoking in non-designated areas. One sign, posted between a school and bus stop near the Music and Dance College, says: “Area around the school. Smoking, snorting, spitting and littering are pro-



Fig. 6 Signage outside of a grade school near the bus station colloquially associated with the music and dance College. Photograph by author.

hibited in public places,” with a 50,000 MNT fine for smoking and a 10,000 MNT fine for spitting⁵ (Fig. 6). Fines are in relation to breaking Mongolian law, their official verbiage reproduced in both Mongolian and English language on a sign located behind City Tower. This sign not only reminds that “CCTV is working” but also includes a phone number one can call to file a complaint (Fig. 7).

On a characteristic sunny, cool spring morning in March 2022, a friend and I met with a high-ranking official from the Ulaanbaatar City managerial institution overseeing the planning and implementation of the “Let’s Make the City Lovely” campaign. We waited in the corridor of the two-story government building in Sansar district for an internal meeting to finish, and were then invited in. We sat at one end of a long, shiny conference table, with Ganbold, a middle-aged man dressed



Fig. 7 Signage detailing Mongolian law forbidding spitting, urinating, defecating, and littering in public. Photograph by author.

in suit and tie, seated at his desk at the other end. After a polite welcome and being offered tea and coffee, Ganbold asked why I had contacted him. I explained that I had noticed the “Let’s Make the City Cultured” campaign signs around the city, and wanted to know more about them. What was the rationale behind the campaign’s inception?

“Recently young people, especially of Ulaanbaatar, have been improving their behavior in society and improving the introduction (*nevtriiilekh*) of the city’s culture every day. But, of course, there are also some inappropriate actions due to the large number of people living in the city” over half of the country’s population, Ganbold mentioned. “It’s been about two and half to three years since the appeal to make [the city] beautiful/comfortable (*tokhijuulakh*) began. We said, ‘let’s fight littering side by side and educate’ (*gegeeruilie*) our citizens to live together in a safe environment for the good of our city.” The campaign aims to create “the healthiest and safest environment possible by adopting the right standards,” and that this is related to Article 16 of Mongolian Constitution,

which guarantees every person the right to live in a healthy and safe environment, Ganbold explained.

How do these health and safety standards connect to the idea of “being cultured”? I asked.

“The city’s culture is that, when a person leaves their home in the morning, they enter social life (*niigmiin amidral*). Even from the moment they cross the road, or drive their car, they enter public relations (*niitiin khariltsaa*). Even from [the moment] they leave their home, to take out the trash, to throw it in the street or in the sorted garbage bins, they will be greeted by the city’s culture.”

While Ganbold described the city’s culture as external to the individual, each person also actively shapes the city’s culture. Each person is responsible for “being cultured” which, according to Ganbold, means no littering, no spitting in public, and following traffic rules.

Here Ganbold describes the need to develop a healthy and safe urban environment, imagined to be achieved through adopting the “right” municipal standards and educating citizens about those standards. As something that belongs to the city, yet each person contributes to, the “city’s culture” relates to both public relations and social life. By adopting certain behaviors – and refraining from others – citizens can contribute in a positive way to the “city’s culture.” The stress Ganbold places on educating citizens, and being educated as a citizen, is a strand that runs throughout campaign signage, sometimes expressed as the need to “self-actualize” or “become conscious” (*ukhamsarlakh*) or simply being courteous to others. At other times, this is expressed as having the right

kind of consciousness (Fig. 8). For the “Let’s Make the City Cultured” campaign, the key is to have a “citizen’s consciousness.”

One gets a sense of the kind of culture the city claims to embody in a 28-minute video posted on the campaign’s “Let’s be Cultured” Facebook page, the opening scenes of which depict young adult artists, musicians, and dancers performing in different public spaces around Ulaanbaatar city. Except for a ballet dancer, wearing a characteristic white tulle skirt and leotard, the artists and musicians each wear clothing that code as traditional national dress, such as a *deel* (tunic) and hat.⁷

A series of posts on the campaign’s Facebook page mostly dating from 2019 depicts by photograph (e.g. stills from CCTV camera footage) ‘real-life’ instances of people not behaving in a ‘cultured’ way. One image depicts an SUV parked in a river, the water of which about a half a meter deep, with a man and woman cleaning the rear bumper and floor mats with river water. The caption says, “We believe that #Ulaanbaatar city car owners will not wash their cars in the river.” A second Facebook post depicts the backs of three men while urinating on the wall of an outdoor sports stadium. The caption says, “When will #Ulaanbaatar city youth become conscious (*ukhamsarlakh*) as 21st century citizens of the city?” As referenced here with urban youth, “uncultured” behavior such as urinating in public is not explicitly associated with people from the countryside. This point was reiterated in discussion with a friend: “City people (*khottiin хүмүүс*) or countryside people (*khödөөний хүмүүс*) – it doesn’t matter. Anyone can act in an uncultured manner.”

However, Ganbold mentioned that not everyone is equally to blame for breaking the city’s aspirational cultural code. He detailed rising tensions in recent years between longer term residence of Ulaanbaatar and newcomers from the countryside:

“There is a tendency for native (*unagan*) citizens of the city to complain that the orcs (*orkuud*) of the countryside are coming and littering trash, scouring (*davkhikh*) the city, and violating traffic rules, such as exiting from a ‘no-exit’ location. But if you consider it, for a while now, the exchange of online information by Facebook is good in all rural areas, so even though they are our countryside people, our city is one big family (*ail*). The dif-



Fig. 8 Campaign sign at a construction site behind the Flower Centre. Translation: ‘Citizen’s consciousness, healthy trash-free environment’. Photograph by author.

ference [between countryside and city culture] is narrowed if you understand that ‘it’s lovely to be cultured’. Of course, during the time when online information/media was bad [i.e. impoverished], people that came from the countryside to Ulaanbaatar were shocked, they hadn’t seen any of this. Now that everything is open, people themselves want to be lovely, and dress themselves in clean clothing.”

Here Ganbold details the assumption held by the Governor’s office of Ulaanbaatar about the supposedly universally held value among countryside people in appearing and behaving more like city dwellers, and that the spreading of this value has been greatly aided by 4G networks extending social media platforms to rural places (see also Munkherdene, forthcoming). As a kind of nucleus of the nation’s culture, Ulaanbaatar and its governing body owe it to their countryside-dwelling kin to extend the kind of modernity that has been developing there outwards, made much easier than before by social media, internet, and 4G coverage available in increasingly more rural places.

While the “Let’s Make the City Cultured” campaign doesn’t explicitly target countryside people, it does send clear messages implying a “cultural” divide, as exemplified in a sign displayed on the front door of Terelj Hotel, a high end, resort-like hotel, spa and restaurant. While still within the city limits, Terelj Hotel is nestled within the Gorkhi-Terelj National Park, some 40 km from central Ulaanbaatar. The least expensive double room in off peak season costs 650,000 MNT, approximately half of the average monthly salary which, in 2022 was 1,330,400 MNT, or 465 USD. As a reminder for countryside people that this establishment is frequented by affluent urbanites especially on the weekends, two signs are posted at the hotel’s entrance, asking patrons to wear a mask and refrain from spitting. Both co-sponsored by Ulaanbaatar City and World Vision, the lower sign reads “LET’S GET USED TO THE BIG CITY’S CULTURE!” (Fig. 9). The sun-bleached sticker depicts a red circle-backslash symbol inside which the shadow outline of a person spitting, and reads, “Don’t snot/spit.”

Given that the sign is posted in a prominent and highly visible location on its property, here it seems that Terelj Hotel – with the help of signage

from the Governor’s Office of Ulaanbaatar and World Vision – wants to remind clientele and staff that, while located in a rural setting, Terelj Hotel is an establishment in which the ‘cultural norms’ of the city apply.



Fig. 9 Appeals to ‘get used to the big city’s culture’ at the entrance of a high-end hotel. Photograph by author.

Here the classist connotations of the “Let’s Make the City Cultured” campaign, whether intended or not, are noticeably apparent. Considering ‘the city’ (as delineated by the Governor of Ulaanbaatar’s office) as Bourdieusian field is helpful, as the analytic brings with it tacit rules that govern interactions within, about which the ruling class (within a given field) has a better “feel for the game.” As indicated by the Terelj Hotel sign, the city as field is not limited to urban areas, further illustrating the aspirational scope of the “Let’s Make the City Cultured” campaign.

The set of tacit rules that govern interactions within the city as field is clearly spelled out by the Governor of Ulaanbaatar City’s office and, as such, normatively prescribed. “Being cultured” is the principle social value of this field, and also ex-

pressed as universal value to all Mongolians, but to which city dwellers have better access. Even as countryside and urban dwellers resist class-based distinctions, such state-circulated public health messaging discursively seeks to produce a particular kind of bourgeois subject.

One can catch a glimpse of the push back against such narratives circulated by the Governor of Ulaanbaatar City’s office, due to the comment-able feature inherent to social media platforms where dissenting opinions can be expressed. Two posts on the “Let’s Make the City Cultured” campaign’s Facebook page include photos of cars parked on the sidewalk. In each post, a commenter challenges the claim that this is straightforwardly behavior to be condemned. A commenter in the post of Fig. 10 explains that, “There are two sides to the story. If land planning was done correctly from the beginning, there wouldn’t be a problem for anyone.”

As a revise-able field, “the city” includes dissenting and critical voices, troubling the notion that campaign designers and disseminators unproblematically designate “cultured” behavior in a top-down model. Due to the affordances of social media platforms like Facebook, multiple actors revise the narrative, in this case, holding the Governor of Ulaanbaatar City’s office accountable. This space for resistance against potentially clas-

sist ideological messaging is in line with ALTHUSSER’s notion that ideological state apparatuses are sites of class struggle:

“The class (or class alliance) in power cannot lay down the law in the ISAs as easily as it can in the (repressive) State apparatus [...] because the resistance of the exploited classes is able to find means and occasions to express itself there, either by the utilization of their contradictions, or by conquering combat positions in them in struggle” ALTHUSSER 1971: 140).

As illustrated in the comment drawing attention to poorly executed city planning, there is room for resistance within the “Let’s Make the City Cultured” ideological campaign, by publics targeted or exploited by such messaging.

A citizen’s duty to be cultured: State socialist health propaganda

As seen above, central to the “Let’s Make the City Cultured” campaign and related public health messaging is the linking of public order, health, safety with “self-actualized,” considerate, and “cultured” behavior, which is understood to be achieved through adopting particular standards and educating citizens of those standards. The appeal to citizen’s consciousness of the “Let’s Make the City Cultured” campaign – and focus on

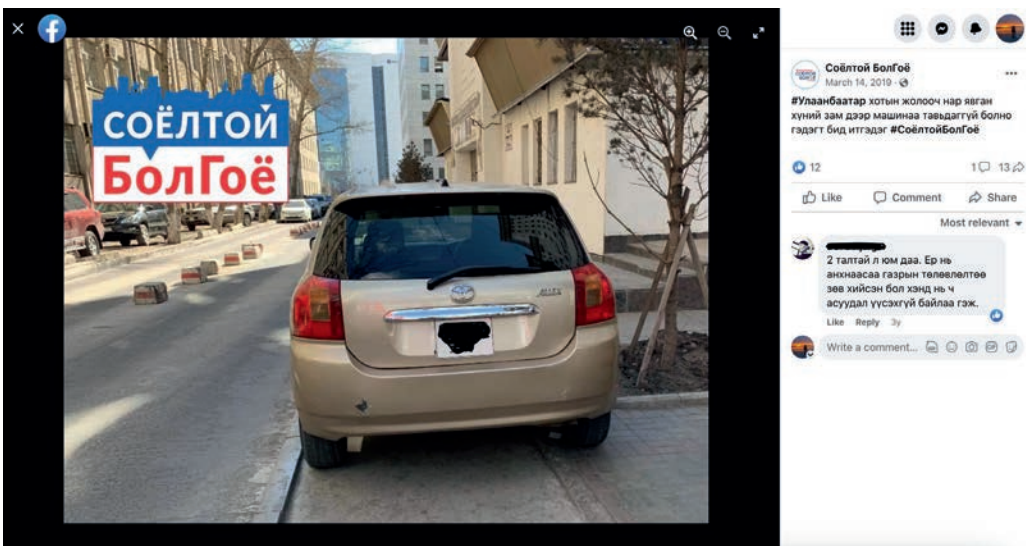


Fig. 10 ‘We believe that #Ulaanbaatar city drivers will not park on the sidewalks. #It’sLovelytoBeCultured’.

raising awareness through educative campaigns in COVID-era Mongolia more generally – bears particular resemblance to the ways in which society under state socialist regimes was expected to transform. If, for MARX, societal change was to begin with the base (the means of production and relations of production) to then change the superstructure (i.e. politico-legal institutions and ideology), actually existing socialist regimes inverted that model; as GLAESER reminds,

“In spite of frequent invocation of Marx in socialist rhetoric, then, socialist practice was in an important sense very un-Marxian. It inverted the Marxian ‘inversion of Hegel’ once more in developing what was, in effect, a consciousness-driven model of social transformation.” (GLAESER 2011: 67)

Much of the current public messaging around “being cultured” and either promoting or denouncing certain behaviors or habits is reminiscent of state socialist period propaganda (*urialga loozon*) from the mid-20th century. This trend is consistent with the ways in which state-led propaganda sought to influence health-related public behavior in multiple state socialist or late-socialist contexts, including China (LYNTERIS 2013), Cuba (BROTHERTON 2012: 56–83), Vietnam (LE & BLOCK 2023) and Tanzania (LAL 2010: 7). While the Mongolian People’s Republic (MPR) was not formally part of the USSR, it was a satellite state; the Mongolian People’s Revolutionary Party (MPRP) of the early 1920s was Soviet-backed and followed policy disseminated from the Soviet Union. During the state socialist era, the dominant Soviet political culture gained particular value in public life. While elite Party members at times disagreed on the level of Soviet involvement in Mongolian affairs, especially economic, the local variant of Marxist-Leninism heavily promoted Mongolia as part of the same socialist ecumene.

One of the MPRP’s central goals after consolidating power in the 1920s was to create a “new culture” that would be “national in form, socialist in content, and international in characteristics.” While cultural transformations of the early MPR (1921–1940) focused on eliminating the dominance of religious ideology – primarily targeting the Tibetan Buddhist establishment, but also including shamans – by the late 1950s and early 60s more relaxed communist ideological pressures⁸ meant

that cultural aspects of prerevolutionary culture previously denigrated as “feudalist” only a few decades prior were reimagined and valorized as the “cultural heritage” of celebrated national intellectuals. Across the arts – music, literature, fine arts, and so on – primitive “bad” culture was parceled from “good” folk culture belonging to the proletariat – sometimes the subject of heated debates. “Good” folk culture that could be praised as an aspect of “socialist national identity” was elevated, re-imagined and re-made through nationalist and secular discursive lenses, sometimes including wider European lenses.

Given the early MPRP’s aim to annihilate religious ideology, teachings, and material culture,⁹ it is somewhat ironic that the Mongolian *soyol* was selected as translation of the Soviet *kul’tura* concept, for the proximity to religion the former entailed; in prerevolutionary society, *soyol* was associated with teaching, doctrine/religion, ethics and nurturing (TSETSENTSOLMON 2015: 427), and closely related to the Buddhist monastic establishment. This can be seen during the decade-long Bogd Khaanate divine monarchy (1911–1921), from which phrases like “to obey the culture of the Bogd” (*Bodgiin soyold dagah*) were used, retaining not only religious but also political and administrative connotations that trace from the Qing dynasty and usages of the Manchu word *wen* (culture) that meant decree or legislation (ALTANZAYA 2007).

Soyol was recruited into the revolutionary project to transform society, into one that was modern, educated, and urban. It was also mobilized to reflect the new secular educational values of the socialist state. To “have culture” or “be cultured” meant to be well-educated, and the terms “educated” (*bolovsroltoi*) and “cultured” (*soyotoi*) became nearly synonymous. Mass literacy campaigns linked education (*bolovsrol*) and enlightenment (*gegeerel*) to form terms such as *soyol bolovsrol* or *soyol gegereel* (see also SNEATH 2009: 76).

Alongside the introduction of Soviet medicine from the earliest days of the MPR, the state targeted hygiene, health, and cleanliness (*ariun tsever*) in an effort to transform daily routines, habits, and ways of thinking. Such messaging eventually coalesced into cultural campaigns (*soyoliin dovtolgoon*) by the 1950s directed at hygiene and elimination of general diseases, the improvement literacy

and education, protection of children, and maintenance of public order; cultural campaigns were expected to usher in “a cultured mode of living” (*ahuin soyol*) (see also SHAGDAR: forthcoming). The state introduced European habits of personal grooming, such as daily washing of hands and face, and brushing of teeth, and regular cleaning of one’s body, hair and clothing; and using regularly cleaned bed linens. An “hygiene corner” became a staple in every *ger* (yurt), located upon entering to the left and consisted of a washstand and bowl.

“These habits were compulsory at the schools that had been established around the country, and in rural districts people were instructed that they should have washbins, soap and clean bed linens available for inspection at all times. Local cadres would tour encampments checking that households complied with these standards, and failure was punished, in some cases by public humiliation – such as having to display a large board painted to look like a pig outside one’s home.” (TSETSENTSOLMON 2015: 427)

Soviet hygiene campaigns, largely speaking, were cast as educative, intended to uproot bad habits and immoral actions that lead to unproductivity and disease as “hygiene became part of an all-encompassing ideology of enlightened Soviet behaviour” (STARKS 2008: 7). This can be seen in the push to educate Mongolians in terms every person was thought to understand: widely-distributed posters with short descriptions accompanied by an easy-to-follow set of images. State socialist propaganda (*urialga*; also *ukhuulga*, *surtag*) linking “being cultured” to practices that promote hygiene, cleanliness and safety conferred a sense of personal responsibility for one’s own actions, which would not only keep oneself healthy, but those around them. This sense of responsibility scaled up to the nation-state; the title of the poster in Fig. 11 (likely from the 1950s or 60s) reads, “Destroy the lice that cause typhoid fever. This will benefit yourself and your country!” and depicts in the central large panel a smiling youth demonstrating the “joy and happiness” (*bayar*, *jargal*) of bathing.

One technique to deliver health and hygiene “promotional materials” as they were sometimes called was to focus messaging on cause and effect; often the result of what was written in text was il-

lustrated through image, showing either a bright scene with people smiling (as in the above poster encouraging lice destruction), or the opposite: a dark and bleak scenario one should avoid. A formula for such messaging could be read as: “if you do what x [text] instructs, your life will look like y [image].” An example of illustrating positive and negative scenarios can be found in a poster from 1945 (Fig. 12) in which the three images mirror scenarios, on the left coded as “bad” and on the right, “good.” Through juxtaposition of positive and negative examples, the poster instructs how to “disinfect the interior of the home,” the importance of food safety, and protecting the water one drinks from polluting elements that might be present in the topsoil, such as those deriving from livestock carcasses and feces, as well as human activity, such as washing clothing.



Fig. 11 Lice and Typhoid Fever poster. Artist and year unknown (ROSSABI 2017: 135). Image courtesy of YUKI KONAGAYA.

The introductory text at the top reads “People! Remember that you can create a clean, healthy, and comfortable environment by working hard and diligently. The more you work to purify your home, the more you can clean and become a role model to others.” Showing, or setting, an example (*ülger duurail(al)/jishee üzüülekh, ülger tursh-laga bolokh*) for others – whether striving to set a good example, or avoiding setting a bad one – is a consistent trend for such public health messaging. Through sets of instructive text and image, the title of the poster featured in Fig. 13 reads, “Set an example for children of how to keep themselves clean.” The image depicts an adult man smiling, standing in a modern, Western-style bathroom demonstrating to a boy (presumably his son) how to keep clean. The caption below the image reads, “Teach children how to fulfill the requirements of practicing personal hygiene.” The four-part panel at the bottom depicts a woman wearing an apron showing by example a girl (presumably her daughter) how to brush her teeth. The text below the set of images reads, “Setting a good example



Fig. 13 Propaganda poster illustrating the importance of setting a good example for children. Artist and year unknown. (ROSSABI 2017: 134). Image courtesy of YUKI KONAGAYA.

and demonstration helps the child master the skill quickly.

In some cases, the educational messaging of such posters involves making the viewer aware of the agent causing the illness by making it visible. By enlarging the microscopically small virus, bacteria, parasite, and so forth, the artist can then portray how the bacteria or virus is transmitted. In the “good example and bad example” poster shown in Fig. 12, in the left column are three magnified images of the illness-causing culprit, reminiscent of the circular field as viewed through a microscope. The viewer sees a person bedridden from tuberculosis, intestinal tapeworms brought into the home by a dog, and intestinal typhoid and dysentery hidden in food and drinking water.

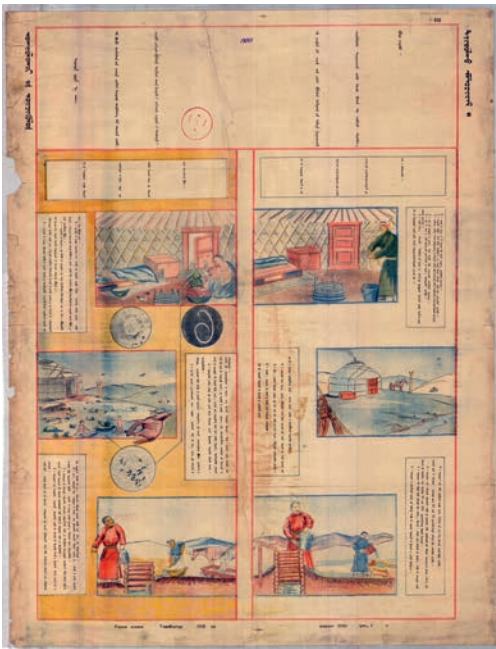


Fig. 12 Creating a clean, healthy, and comfortable environment, illustrated through positive and negative examples. Artist unknown. Image courtesy of YUKI KONAGAYA.

Interlinking values in public life across political regime changes

Upon closer inspection, many of the above-mentioned common themes of health and hygiene related state socialist-era posters – illustrating good and bad behaviors through cause and effect, keeping oneself healthy as one’s duty as citizen, setting a good example for others, and making the illness-causing agent visible as illustration to educate about transmission – appear in COVID-era public health messaging. The “Let’s Make the City Cultured” campaign’s Facebook page includes posts that take up the importance of parents not setting bad examples (*buruu ülger durailal üzүүлэхгүй*) for their children. One post depicts a photograph (likely from CCTV footage) of a man stepping over a fence-like, waist-high road divider in central Ulaanbaatar with a young child in tow. The commentary states, “We believe that #Ulaanbaatar city parents are able to show their children a good example of how to cross at crosswalks. #It’sLovelytobeCultured (#Soyoltoibolgoi).” A second post shows a photograph taken of two children with their heads and upper torsos out of the sunroof of an SUV cruising through central Ulaanbaatar. The caption states, “We want to keep #Ulaanbaatar city parental drivers from setting wrong examples for their children. #It’sLovelytobeCultured.”

COVID-related health messaging also features a microscopically small virus made visible by the naked eye through illustration, similar to the “good example, bad example” poster depicted in Figure 11. In a one-minute animated educational video entitled “Let’s [All] be Cultured” (*Soyoltoi Baitsgaay*), sponsored by World Vision and circulated during the height of the COVID-19 pandemic, a man at a bus stop spits on the ground near a child. The camera zooms in on the spit to show red, menacing-looking bubbles meant to represent infectious diseases like COVID-19 that hide inside saliva (Fig. 14). The bus arrives, and the following scene depicts the boy on the bus, already infected. The red virus bubbles linger around his face as he stands next a seated, elderly woman. He coughs, and the red virus blobs travel away from him in all directions, some of which towards the elderly woman. Here we also see illustration of wrong behavior through cause and effect.

Reading such similarities in health-related messaging from state socialist and pandemic era Mongolia alongside ALTHUSSER’s scholarship on ideological state apparatuses reveals a few things. Even as the disseminators of COVID-era public health messaging include the state but also extends to trans-national organizations like World Vision, the World Health Organization, and Asian Development Bank, as well as owners of private establishments such as shops and hotels, there is consistency in messaging from before and after

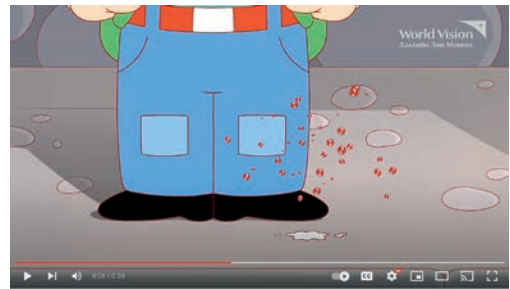


Fig. 14 A still shot from the “Let’s [All] be Cultured” video, sponsored by World Vision and publicized on Youtube (World Vision 2020).

the socio-economic and political rupture of the 1990s. This helps us say something about ideology with respect to ISAs. In the case of the examples offered here, institutional powers beyond the state circulate ideological messaging about “cultured” behavior that aligns with state interests in producing bourgeois subjects. That the majority of these trans-national health, financial and/or development organizations are based in the global north (and some of the signage in English language) holds particular weight, both in terms of messaging in public culture about the importance of Mongolia’s “Third Neighbors” (i.e. geopolitical powers beyond Russia and China) and mobility trends to Global North countries, especially for higher education (LOO 2017).

The naturalized social value of ‘being cultured’ – entailing associations of being educated, “self-actualized,” having “citizen’s consciousness,” upholding one’s civic duty, and engaging in safe and healthy daily habits – is not the only idea to have endured across the socio-economic and political changes of the 1990s. There are res-

onances between the two periods with respect to how social change is imagined to take place, by institutions with the means, power and authority to circulate such messages: first, in the assumption that people follow “cause and effect” public health messages about how their behavior will affect their own health and that of others in a straight-forward and predictable way. This supposition hinges on the idea that humans are fundamentally rational, consistent, and autonomous choice-makers who, once properly educated, will continue to make the “right” decision. We know social behavior to be much more complex, and mediated by entanglements of social relation, such that a parceling out of social rules or “norms” from individual choices made by an atomized subject is overly reductive and prescriptive in most cases (ENGLUND 2012).

Second, considering health-related propaganda from the mid-20th century and COVID-era with respect to ideological state apparatuses, reveals how, in both instances, messaging entails the assumption that social change takes place by exemplars adopting the “correct” behavior that others will want to emulate.¹⁰ “Setting a good example” or avoiding setting a negative one, with regards to health and safety measures carries powerful weight today, not only as it is mobilized as a strategy by the “Let’s Make the City Cultured” campaign. Commenters, presumably unaffiliated with the Governor of Ulaanbaatar’s office (yet also a self-selected group, interested enough to “follow” the campaign on Facebook), urge parents to set good examples for their children. Here ordinary citizens are involved in the process of interpellation, fruitfully complicating ALTHUSSER’s top-down model.¹¹

Given the moral importance of exemplars during the state socialist period, as illustrated in the posters above, one might be invited to read HUMPHREY’s (1997) seminal work on the topic with a different inflection. In “Exemplars and Rules: Aspects of the Discourse of Moralities in Mongolia,” HUMPHREY (1997: 25) argues that ethics and morality for Mongols coalesce more around the relationship between individuals and exemplars than around rules or customs. Perhaps it is less about the Communist government “hijacking” pre-existing Indigenous discourses

(*ibid.*), which has been interpreted by some scholars using a culturalist lens, and more about values circulating in wider Soviet political economy, and the powerful ability and long lasting effects of the authors of such messaging to link ideas about citizenship, health, and education together with a normative sense of social progress, in ways that ultimately promote state interests.

Concluding thoughts and the enduring relevance of a postsocialist analytic

In this article, I have suggested that BOURDIEU’s notion of fields is helpful in understanding COVID-era public health messaging from the “Let’s Make the City Cultured” and allied campaigns, for the tacit rules or social norms the analytic brings with it. Social media platforms amplify the reach of the Governor of Ulaanbaatar’s office and other institutions like World Vision to change those tacit rules, by normalizing them as features of a national “culture” that everyone should want to be a part of.

I have also suggested that reading such campaigns alongside ALTHUSSER’s work on ideological state apparatuses reveals a few things. First, it helps to focus on class as an aspect of social relations that is co-constitutive with socio-historical processes and shaped by power relations. Even as countryside and urban dwellers resist class-based demographic or sociological distinctions, by delineating the “city’s culture” and associating it with bourgeois values, the “Let’s Make the City Cultured” campaign participates in discursive class-making, however partial and incomplete, and however variously received by different publics. The campaign subtly and by implication makes claims about something that could be called “countryside culture” without explicitly having to do so, as the countryside (*khödöö*) already holds the position of the city’s antipode in public thought.

Second, reading COVID-era public health messaging alongside ALTHUSSER’s work on ideological state apparatuses highlights instances in which social values, their “packaging” and modes of dissemination endure across political regime changes. Much scholarship in ex- or post-socialist scholarship tends to privilege a central rupture (MÜLLER 2019) – the collapse of state social-

ism – but there is, of course, the other side of the “rupture” coin to consider. While sometimes described as continuities, considering the duress of historical endurances better captures the ways in which, as opposed to inert relics of the past, histories are uneven and contingent, folding back on themselves “and in that refolding, reveal new surfaces and planes” (STOLER 2016: 26).

Alongside enduring social values of “being cultured,” well-educated, fulfilling duties as citizen, presenting oneself as clean, and so on, in the “Let’s Make the City Cultured” campaign we can see the enduring effects of socialist ideas about the role of the state (DUNN & VERDERY 2015) by those in charge of making, promoting, and disseminating public health and safety messages. We also see endurance in assumptions about how social change is imagined to take place: that human beings, as rational, consistent, and autonomous, once taught about how behavior influences one’s own health and that of others, will predictably make the “right” choices. Oversimplification of human behavior can be claimed too for ALTHUSSER’s model of interpellation, in its dogmatic assumption about the all-encompassing power of ideologies, and the lack of accounting for individual human agency.

In this case study, postsocialism can be helpfully utilized not as universalizing descriptor of societies, nor as a singular discursive lens that can be evenly applied across the former state-socialist world (PLATT 2009: 9–10). Instead, I think that postsocialism as analytic can be harnessed to do specified work, used in certain contextualized instances. With respect to interlinking values in public life associated with health, exemplarship and citizenship as explored here, a postsocialist analytic brings to light similarities across disparate political regimes, particularly the salience of social progressivism, naturalized value in being a subject of the state, and importance placed on modern science. Perhaps postsocialism’s days are over as an “-ism,” and instead more helpfully mobilized to qualify particular social forms.

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Notes

- 1 Also translated into English as ‘Mayor’.
- 2 BRANDEL & MOTTA (2021) tell us that is a feature of concepts more generally, as lived-in and experiential aspects of our lives.
- 3 An important break from Gramscian theory is found in how social transformation would take place; whilst GRAMSCI (1971) promoted the idea that intellectuals would organically arise to creatively devise ways to actualise communism, ideology for ALTHUSSER is considerably more structural and deeply embedded in capitalist social relations. Entire systemic collapse is needed for individuals to be able to think outside of ideological forces.
- 4 Such critiques also suggest that ALTHUSSER’s rendering of ideology ignores successful instances of political or work-based collective activism, even during a time marked by increased precarious labour conditions worldwide (see LAZAR & SANCHEZ 2019).
- 5 Approximately 15 USD and 3 USD, respectively, during the time of fieldwork.
- 6 A literal translation of *gegeerüülekh* would be ‘to make enlightened’, but in this context I’ve chosen to translate it as ‘to educate’, other translations of which found in *bolovsrol olgokh* and also *surgakh*.
- 7 Interestingly, according to the campaign, ‘being cultured’ doesn’t always map onto practices considered cultural in the sense of being ‘traditional’, such as offering the top of tea or milk, typically in the early morning (*deej örgökh*), as criticized on their Facebook account.
- 8 These were felt both within Mongolia’s borders and were part of a larger trend across the sphere of Soviet political influence. This ‘Post-Stalin Thaw’ period saw increased freedom of information in the arts, media and culture and witnessed a more relaxed approach to forms of entertainment existent in public culture. TSETSEN-SOLMON (2015: 428-9) notes that Mongolian intellectuals such as BYAMBYN RINCHEN (1905-1977) and TSEDIN DAMDINSÜREN (1908-1986) (although they disagreed on a number of issues) promoted the importance, variety, and unique characteristics of Mongolian forms of art and literature, arguing that they be reclaimed as valuable aspects of pre-Revolutionary heritage. This formed part of a movement of ‘a more self-confident and cosmopolitan national elite who were aware of the national culture of other socialist elites, particularly Russia’.
- 9 This aim, both in theory and practice, was neither inevitable nor a singular event, but rather a complex process of dealing with the ‘lama question’ in an effort for the socialist government to be seen as legitimate by the population (KAPLONSKI 2014), which had been ruled by Buddhist feudal theocracy in the decade leading up to

the Revolution. It took nearly a decade and a half for the decision to be made; beginning in 1937 and for a period of eighteen months, at least 22,000 people of a population of 750,000 were killed, half of them Buddhist lamas (KAPLONSKI 1999: 97) and many of them educated and political elites deemed enemies of the state. The Soviet-Mongolian government ordered the destruction of 700 Buddhist monasteries, their printed materials and iconography. While some Buddhist lamas continued practicing 'in secret', the extent of lost religious knowledge was severe, as these purges 'annihilate[ed] all that was best and most sophisticated about native Mongolian culture, philosophy and art' (HUMPHREY 1992: 375).

10 This is distinct from, but certainly compatible in many ways with, the moral authority of the past in Mongolia, as HUMPHREY (1992) details.

11 I am thankful to my reviewer for mention that, during the COVID-19 pandemic, ordinary citizens were discussing the need to revive the state-socialist era 'cultural campaigns'.

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Visual Expressions of Embodied Risk

Body Maps as a Means of Reflecting and Understanding the Meaning of Health Risk in Research and Teaching

SASKIA JÜNGER & MARIYA LORKE

Abstract With increasing opportunities of early detection of risk in biomedicine, the communication of statistical likelihood of disease has gained importance. Risk communication is committed to the support of risk literacy, assumed to be a prerequisite for making informed decisions to minimise one's risk. Graphical representations play a crucial role in this context; among others, stylised human silhouettes are employed to visualise likelihoods, for example to indicate the number of persons out of one hundred who will or will not get the disease. While this may support risk literacy in terms of more easily 'grasping' abstract statistics, still a risk likelihood is difficult to comprehend in terms of its meaning for one's individual life. So what if this principle is inverted and the stylised human silhouette is used instead to visualise the individual and collective meaning attributed to a certain – actual or envisioned – disease risk? In the context of a study on health literacy among persons with an increased disease risk, we employed body maps in research and in teaching. In the research project, we conducted narrative interviews with 20 persons who had been informed about having an increased risk for familial breast and ovarian cancer or psychosis. Towards the end of each interview, we invited our informants to do a body mapping exercise, using a stylised human silhouette on a sheet of paper and asking them to sketch their risk. In teaching, we invited medical students attending an ethics seminar to do a body mapping exercise in small groups based on a case example, using a stylised human silhouette on a flip chart sheet.

Keywords body maps – health risk – risk understanding – research methodology – teaching

Introduction

In this contribution, we analyse the potential of Body Maps (BMs) as a visual methodology and creative technique to explore embodied representations of disease risk in the context of research and education. BMs are representations of the human body containing a person's narrative and telling a story about a certain aspect of their life (VAN RANTWIJK 2021). In a medical context, they are well-known for the documentation of symptoms such as pain. Their historical origin as an arts-based method is described as being in South Africa as a therapeutic intervention for women living with HIV/AIDS (GASTALDO *et al.* 2012). Later, next to variations in their therapeutic use, BMs were also adapted as an arts-based activity for educa-

tion and as a (participatory) research data collection tool (LYS *et al.* 2018: 1185-1186). In the field of health research they find application to elicit subjective perceptions of one's health and identify health-related issues (GASTALDO *et al.* 2012: 11). BMs have been employed in different areas, for example to explore healthcare experiences of men and women with a diagnosis of fibromyalgia (SKOP 2016: 29-43); subjective experience of bodily activity such as yoga (VAN RANTWIJK 2021); sexual health (LYS *et al.* 2012: 1186); HIV/AIDS; eating disorders; chronic pain; occupational health (GASTALDO *et al.* 2012); and human-computer interaction (VAN RANTWIJK 2021).

Epistemological and methodological background

The rationale for the use of images of the human body to tell a story is manifold and rests on the appreciation of arts as a source of reflection concerning a person's inner and outer worlds that can do more justice to the depth and complexity of embodied experiences than words alone (SKOP 2016: 29–43). Epistemologically, this can be argued from both a phenomenological (KLEIN & MILNER 2019) and a constructivist (SKOP 2016) perspective. By means of visual methodologies, people have the opportunity to explore and draw their awareness to phenomena in unusual ways and can thereby make meaning of experiences that may not be accessible for or difficult to share in the form of a verbal account (LYS *et al.* 2012: 1186). BMs also have integrative effects, assessing the intersection of global and local contexts, connecting times and spaces (GASTALDO *et al.* 2012) as well as mind, body, and social context (SKOP 2016: 29–43). Next to the methodological strength for collecting rich data in research, the intervention character of body mapping is emphasised in terms of its potential for introspection, reflection, processing experiences, self-expression and liberation through storytelling, creating narratives and validating the legitimacy of one's experiences, and even altering body perception (SKOP 2016: 29–43; LYS *et al.* 2018: 1185–1198; VAN RANTWIJK 2021). Body mapping also has interactive, collaborative features – between researchers and participants, and in group settings also between participants. Here, the effect of societal storytelling and empowerment by transforming individual into collective experiences is described as key (SKOP 2016: 29–43). The collective sharing of narratives may entail a cathartic, validating, and healing effect; and also help to co-create meaning and power of definition opposing dominant medical discourses concerning health and body.

This is of particular relevance in the context of evidence-based medicine (EBM) as the dominant framework for scientific knowledge generation in 'Western' medicine (JÜNGER 2024). While EBM privileges certain forms of evidence (generalizable and 'objective') and certain codes of articulating and presenting knowledge (in a standardised, impersonal way) (CAREL & KIDD 2014: 530), patients "live in a messy, idiosyncratic, and

unpredictable world" (GREENHALGH *et al.* 2015: 1). EBM's strict specifications as to what counts as knowledge hence does not encompass a diversity of understandings and meanings of health (GREENHALGH *et al.* 2015: 2; JÜNGER 2024). This is, amongst others, due to the low status of experience, anecdote, as well as tacit (personally embodied and socially shared) knowledge in the hierarchy of evidence (GREENHALGH *et al.* 2015: 2). In consequence, patients' views and stories are not considered as legitimate source of knowledge or evidence in medical communication and knowledge production, which implies a reduction of complexity (GREENHALGH *et al.* 2015; JÜNGER 2024). This deprivation of the opportunity to contribute to knowledge and meaning has been described as epistemic injustice (CAREL & KIDD 2014).

Alternative ways of knowledge generation and communication have been proposed to account for idiosyncrasy and open up a space for more epistemic justice (CAREL & KIDD 2014; GREENHALGH *et al.* 2015; JÜNGER 2024). An integrative epistemic opening of the restricted EBM paradigm has been suggested to allow for a greater diversity of health-relevant perspectives and methodological approaches (JÜNGER 2024). This includes creative narrative and arts-based techniques and phenomenological evidence on lived experiences of illness and healthcare (CAREL & KIDD 2014; GREENHALGH *et al.* 2015). CAREL & KIDD argue that phenomenology can help to "identify and articulate the tacit structures that underpin one's experience and engagement in the world" (2014: 537). In this regard, BMs can be considered as valuing the richness of individual accounts, "moving away from a narrow understanding of illness as a biological process, towards a thick account of illness as a new way of being in the world." (CAREL & KIDD 2014: 538).

In a similar way, they can constitute a salient didactic tool in the context of medical education in order to sensitise for the affective and ambiguous experience of health and illness; and to create a counterweight to collective modes of dealing with medical uncertainty such as intellectualisation and operationalising health-related problems in probabilistic, scientific terms (FOX 2000).

In line with the findings of a systematic review on body mapping (DE JAGER *et al.* 2016), only a

minority of articles address the use of body mapping for teaching purposes. Nevertheless, insights from existing research on medical curricula over the world provide starting points for the assumption that BMs can be a fruitful teaching tool for several purposes. Some authors (e.g. DOUKAS *et al.* 2012: 334–341, ROBERTS 2021: 1075) argue for the immense importance of arts and humanities in medical education as enabling factors for the development of medical professionalism, inspiring creativity and critical thinking. Furthermore, skills of eliciting and interpreting patients' stories are crucial for the preparation of medical professionals (DOUKAS *et al.* 2012: 334–341). BMs can contribute to the development of new teaching approaches in medical education that enable the flowering of empathy and resilience (LAUGHEY *et al.* 2021: 1941–1950) on the one hand and training students' skills in interpreting the social and cultural dimensions of the health-illness process (QUINTERO 2014) on the other hand. Body mapping can be applied in the field of youth education to encourage learning in topics associated with stigma and shame (CHENHALL *et al.* 2013: 123–132) and also to encourage students to increase their self-awareness on the link between body and mind (EMPOWERING EDUCATION 2016: 4). Equivalently, body mapping can be used to increase teachers' self-awareness on how their "personal lived experiences" influence their perceptions about teaching (GRIFFIN 2011: 169–192).

Body-map storytelling in the context of disease risk

The challenges of translating individual illness experiences into medical terms and vice versa are well documented in anthropological and social sciences research (KLEINMAN 1978, NAPIER *et al.* 2014). With increasing opportunities of the early detection of risk in biomedicine, the communication and translation of statistical likelihood and risk of disease has gained more and more importance (FOX 2000, JENKINS *et al.* 2005).

Technical progress in biomedicine allows for an increasingly fine-grained 'unveiling' of the body's inner space (FOUCAULT 1973: 166). While Foucault had introduced this notion in relation to the opening up of the human body and the analysis of tissues in pathology, during the last decades

more and more refined techniques of shining through (x-ray, imaging techniques), fragmenting (genome sequencing), and calculating (algorithms, Big Data) the body have been developed (JÜNGER 2024). These are characterised by a higher and higher degree of abstraction, entailing the idea of operationalisability and quantifiability of human existence. Foucault has coined the term 'medical (or clinical) gaze' for this decryption of health-related phenomena and the associated promise of the increasing control of chance (FOUCAULT 1973).

In the context of EBM, risk is conceptualised as measurable uncertainty, entailing operationalisations of (ab)normality, and implying an action-oriented paradigm of prevention (HOYDIS 2021: 93). This measurability of risk is closely tied to notions of controllability and rationality (HOYDIS 2021: 93; LUHMANN 1990: 136). The 'factual' health risks expressed as statistics promise control over unknown events, and require a person's 'rational' appreciation. There are two central problems related to this. First, logically, the reductionistic parameters constituting a risk profile do not represent the whole person and probabilities cannot be applied to individual decisions (LUHMANN 1990: 143; FOX 2000: 8), resulting in an intellectual gap or what Samerski called 'epistemic confusion' (SAMERSKI 2010). Second, the ubiquitous nature of risk has implications for definitions of 'normal' human functioning and a 'normally' functioning human being (JÜNGER 2024: 156). This entails the construction of a problematic body that needs to be monitored and tamed, and the loss of confidence in the resistance and self-healing powers of human beings. Health and disease are always less considered as tangible experiences, but a something that needs to be actively controlled or prevented.

Graphical representations play a crucial role in this context; among others, stylised human silhouettes are employed to visualise likelihoods, for example to indicate the number of persons out of one hundred who will or will not get the disease. But what if this principle is inverted and a stylised human silhouette is used instead to visualise the individual and collective meaning attributed to a certain – actual or envisioned – disease risk?

Arts-based methodology may serve as an approach to this question; the value of creative

techniques and visual methodology in health research and -communication has gained appreciation during the past years, particularly in the context of community-based participatory research (PHILLIPS, CHRISTINSEN-STRYNØ & FRØLUNDE 2022: 391–411). Furthermore, in the context of risk education, body mapping can contribute to dealing with the manifold concepts and understandings of risk, hereby overcoming the missing clear conception of a risk curriculum (EICHLER & VOGEL 2015: 168–183).

BM can be considered a useful resource with regard to the abovementioned epistemic conflicts; they may have the potential for empowerment in a risk discourse dominated by depersonalised, standardised, and generalised knowledge. BMs may be a storytelling technique, allowing to unfold a personal 'health risk narrative' (HOYDIS 2021: 94), and to construct an individual meaning of risk as a way to deal with uncertainty and randomness. Last but not least, BMs may serve as a source for a salutogenic, benevolent introspection – as contrasting the medical gaze that views the body in pathogenic terms of deviance from a designated norm.

To our best knowledge, there is no research on the use of body mapping (a) in the context of dealing with early prediction of increased disease risk, nor (b) for teaching purposes in the field of medical education. With this contribution, we therefore aim to elucidate the potential of body maps and body-map storytelling in research and medical education with a focus on risk and early prediction in medicine.

In the current article, we will first give a short overview of existing research on the methodological particularities and variations of BMs and the process of body mapping. Second, we will introduce our research with a focus on disease risk and describe the findings of our analysis, based on 33 BMs created in the context of (a) narrative interviews with persons with an increased risk of either familial breast and ovarian cancer or psychosis; and (b) seminars with medical students based on a case vignette on early onset dementia. Third, drawing on our findings and experiences, we will provide a methodological and ethical (self-)reflection on the use of BMs in research and teaching.

Methodological particularities and variations of body maps

BM and the process of body mapping can be considered a field of epistemological and methodological discovery. In their manual for the use of BMs in research, GASTALDO *et al.* (2012: 5) distinguish between the BM as human body image, and body mapping as “the process of creating BMs using drawing, painting or other art-based techniques to visually represent aspects of people’s lives, their bodies and the world they live in.” They coined the term ‘body-map storytelling’ to refer to the specific use in research as a data generating method. The outcome of this process is a mapped story consisting of three elements, i.e. “a *testimonio* (a brief story narrated in the first person), a life-size BM, and a key to describe each visual element found on the map.” (GASTALDO *et al.* 2012: 10). While the authors refer to BMs as life-size human body images, variations can be found in the literature; for example, drawings on Miro-boards (VAN RANTWIJK 2021).

They can also be applied in different settings, such as workshops, face-to-face meetings, online via video-call (VAN RANTWIJK 2021), or in focus groups (SKOP 2016: 29–43). For the process of body-map storytelling, a longer timeframe with several group sessions is described (GASTALDO *et al.* 2012; SKOP: 2016 29–43) in order to provide sufficient time for reflection during and also in-between the sessions. To facilitate the process and set the scene, the relevance of suitable prompts is discussed; for example, a list of questions for reflection (SKOP 2016: 29–43) or a box with different visualisation prompts (LYS *et al.* 2018: 1185–1198). Likewise, a variety of art supplies is recommended in order to allow participants to choose the most appropriate material for themselves according to their skills and preferences, and also address concerns regarding their artistic talent. For example, a collage from magazine cut-outs can be an alternative to drawing (GASTALDO *et al.* 2012).

Data analysis of BMs should take into account the abovementioned trinity of data sources (*testimonio*, BM, and explanatory key), as well as the process of creating the BM, in an integrative approach (GASTALDO *et al.* 2012). Different approaches to data analysis can be found in the literature, such as (Constructivist) Grounded Theory (SKOP

2016: 29–43; VAN RANTWIJK 2021) or thematic analysis (LYS *et al.* 2018: 1185–1198) which are considered suitable for the analysis of the stories narrated in the BMs as constructed by people's experiences. To pre-structure data analysis, techniques from the field of visual analysis can be used. For example, ROSE (2012) distinguishes between the level of composition, semiology, and discourse; and SKOP (2016: 29–43) developed a multi-layered visual coding scheme including features such as use of colour, themes and discourses, repetition and location, tone, or elements of design.

Study design and methods

Context

In the context of a study on health literacy among persons with an increased disease risk in four different clinical fields, we employed BMs in research and in teaching. The Project RisKomp was funded by the Robert-Bosch-Stiftung and the study was conducted at the University of Cologne and the University Hospital of Cologne in Germany (2017–2019). Ethics approval was obtained in March 2018, (registration number 18-014) from the Ethics Committee of the University of Cologne. The study's aim was to generate findings on health literacy of individuals at risk of developing Alzheimer's disease, familial breast and ovarian cancer (fboc), coronary heart disease, or psychosis. We employed a qualitative research design and conducted narrative interviews with 34 persons who had been informed about having an increased risk of one of the aforementioned diseases. Findings from the narrative interviews were published previously (HARZHEIM *et al.* 2020; LORKE, SCHWELGER & JÜNGER 2021; LORKE *et al.* 2021), one of the publications also referring to the BMs in the field of Alzheimer's dementia (HARZHEIM *et al.* 2023).

In connection to the project we also conceptualized and conducted student seminars on medical ethics that were dedicated to risk prediction and communication in medicine. The ethics seminars were either part of the regular curriculum of the medical education (07/2018 and 07/2019) or part of a 2-days workshop organised for a selected number of medical students that took place outside the campus (06/2018). During the seminars,

preliminary findings on risk perceptions and risk communication from the RisKomp study were discussed and in this context, BMs were employed as a didactic feature.

For the purpose of this article, we decided to concentrate on three different disease risks – psychosis and fboc for the use of BMs in research and early-onset dementia for the use of BMs in teaching.

Methodology

In the field of research, we invited our informants to visualise their (communicated) disease risk at the end of each narrative interview. For this purpose, we provided the participants with a stylised human silhouette on an A4-sized sheet of paper and a pen or pencil. We asked the participants to draw how they perceive or feel the condition of being at risk within their body. After finishing the drawing, we asked participants to explain their thoughts during the process of body mapping and audio-recorded their testimonies.

In the field of teaching, we invited medical students attending an ethics seminar to do a body mapping exercise. We divided the group into smaller groups of 5–8 students and provided each group with the same case vignette. The vignette presented the story of a young male who was confronted with a high genetic risk of developing an early-onset dementia. We asked the students to read and discuss the case of the young man and encouraged them to put themselves in his shoes. Next, we asked the students to draw a BM of the feelings of risk (from the perspective of the young male) using a human silhouette on a flip chart sheet. After the group exercise was finished, we discussed the BMs and related the different dimensions of the BMs to existing research on patients' perspectives and/or theories on risk. After each class, we made notes on the procedure and the topics of discussion and photographed the BMs.

The iterative process of data collection through the narrative interviews and the integration of assumptions, previous knowledge and preliminary findings in the conceptualisation of the courses for medical students posed many challenges to the development of an adequate strategy of ana-

lysing the BMs. On the one hand, it was essential to refer to our previous knowledge generated by the analysis of the narrative interviews conducted in the RiskKomp study; on the other hand, it was necessary to perform an analysis of the BMs interpreting the data from a different angle. The focus on the methodology of BMs and on answering the question of what can we learn and teach about risk using BMs informed the decisions on the development of the current analysis strategy. We used Reflexive Grounded Theory as a starting point for the analysis inspired by VAN RANTWIJK (2021) who pointed out that “the way you introduce, design, and surround your BM with other data collection activities influences the data you get” (VAN RANTWIJK 2021: 10). That is why we started the analytical process with explicitly collecting our previous theoretical knowledge on disease risk, the findings on specific clinical fields (in this case psychosis and fboc) and a reflection on how we as researchers applied the method of body mapping. This analytical step made it possible to build a controlled distance towards the data and move to the second step, which contained a new, more ingenious approach to well-known data and to open space for new angles of interpretation. In this second step, we embedded the interpretive concepts of composition, semiology, and discourse by ROSE (2023) into our analysis strategy and interpreted the data along the three concepts. On the level of composition we described the location and relation of different images on the map (Table 1); on the level of semiology (or semiotics) we concentrated on the use of symbols and their meanings; and on discourse level we interpreted specific knowledge about the world, which shapes how the world is understood and how things are done in it. Each interpretation step was critically reviewed and discussed by both researchers; herein, the different academic backgrounds (psychology and social anthropology) and related preconceptions were considered. To protect participants’ privacy, any features in the body maps potentially disclosing their identity (such as handwriting) were reproduced. In the following chapter, we will outline the findings of this analysis (1) looking at what we learned about disease risks using BMs and (2) reflecting on the different methodological settings.

Results

Description of the data

In sum, we analysed 33 BMs – 9 in the field of fboc, 10 in the field of psychosis and 14 in the field of early-onset dementia (Table 1). The BMs in the field of fboc and psychosis were performed individually in the context of the narrative interviews while the BMs in the field of dementia were drawn collectively in the context of the teaching units on ethics in medicine based on a case vignette.

On the composition level of the analysis, the majority of the analysed BMs on risk (25 of 33 BM) depicted risk in- and outside the body (Table 1). Details regarding the location of drawings in- and outside the body will be described in the results section further below. On the semiotic level of analysis, in the case of all three risk types, certain symbols were depicted as an expression of danger, body suffering, and (not-) knowing about the risk. The display of the symbols in the BMs on early-onset dementia, which were collectively performed by medical students, was more detailed, elaborated and emotional. In the case of psychosis and fboc, in contrast, the symbols were closely related to certain body parts associated with the medical definition of the disease risk (e.g. breasts and ovaries in the case of fboc, and the head in the case of psychosis). On the discourse level, the BMs in all three risk fields displayed metaphorical meanings of risk, as being situated both in the body and in the environment. The majority of the BMs displayed the following oppositions: danger vs. safety, medical vs. social meanings of risk, knowing vs. overthinking, determinism vs. agency; uncertainty (about the future) vs. control.

Findings of the analyses of the body maps

The analysis of the BMs showed that: a) The drawings on risk are a product of individual experiences related to risk and disease, which turn the unmanageable uncertainty of everyday life into a manageable one; risk is experienced as an enabling phenomenon (GUPTA 2022: 336–344) and is related to identity (BOHOLM 2015). b) The BMs represent shared collective experience and narratives on risk, mirroring society’s symbolic order

	Familial breast and ovarian cancer	Psychosis	Early-onset dementia
Context	Individual narrative interviews (personal experience of risk)	Individual narrative interviews (personal experience of risk)	Groups of students in medical education (case vignette on risk)
Body Maps	9	10	14
Composition level ¹	only inside the body 5 in- and outside the body 3 only outside the body 1 no body map 1	only inside the body 3 in- and outside the body 7 only outside the body	only inside the body in- and outside the body 13 only outside the body a body was not depicted 1
Semiotic level ²	circles (5 BM) and crosses (2 BM) to mark specific body parts arrows and lines to mark specific areas of impact or affected areas in- and outside the body (3 BM) hearts (1 BM) question- and exclamation marks (1 BM)	circles (7 BM); circled or painted areas (2 BM) and crosses (1 BM) to mark feelings associated with risk arrows and lines to mark specific directions of impact and interrelation (4 BM) hearts (2 BM); stickman (1 BM) question mark (1 BM)	chains or belts (7 BM); symbols of bad weather like clouds and rain (6 BM); symbols of weights (5 BM); cemetery and crosses to symbolise the risk of death (3 BM); symbols of losing ground (3 BM) arrows and lines to mark impacts and interrelations (3 BM); wavelike lines to symbolise trembling or fear (5 BM) hearts (6 BM) and human organs (4 BM); sad faces (5 BM) question marks (7 BM)
Discourse level ³	responsibility for maintenance or restitution of one's health metaphorical meanings of risk, as being situated both in the body and in the environment danger vs. safety, medical vs. social meanings of risk, knowing vs. overthinking, determinism vs. agency; uncertainty (about the future) vs. control	boundaries between 'normality' and 'insanity'	medical power of definition pervasiveness of diagnosis

Tbl. 1 Data analysis according to the analytical framework for visual data by Rose (2023).

and boundaries (DOUGLAS & WILDAVSKY 1983).
 c) The visual representations of risk perceptions on the BMs are related to respective coping strategies as purification practices (DOUGLAS & WILDAVSKY 1983).

a.) Risk as a product of individual experiences, enabling phenomenon and related to identity

It is well known from previous research that the feeling of a certain disease risk is closely related to individuals' previous experiences with the illness (SANDERS *et al.* 2007: 510–520).

The analysed BMs in the field of fboc displayed several further dimensions of individual experiences that impact individual risk perceptions (Figure 1). One BM demonstrated the fluid border be-

tween felt risk and health complaints in general, depicting knee pain on the same level of importance as cancer risk (fboc_01). Similarly, another BM depicted risk as distributed in one specific body area (the chest/breast area) and the study participant explained her drawing on risk as strongly associated with the feeling of as it were already having cancer (fboc_09). Another participant, who had already had cancer, depicted risk in her BM based primarily on the feeling of stress and pressure caused by the fear of cancer recurrence (fboc_07). Another individual experience with risk is referred to as a diffuse feeling. Drawing techniques like crossed diagonal lines marking the whole chest area (fboc_09) or the use of unclosed circles in the chest and lower belly areas (fboc_10) may be interpreted as depicting such a

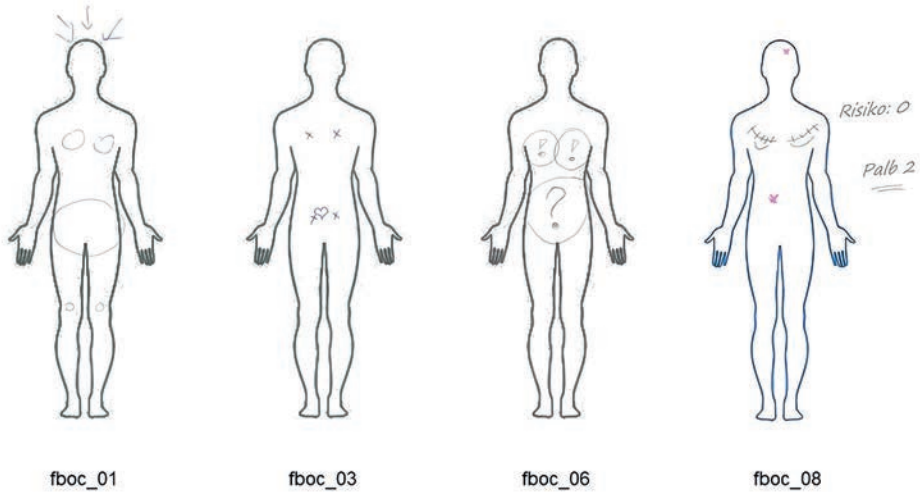


Fig. 1 Selected body maps from the field of increased risk of familial breast and ovarian cancer.

diffuse feeling of risk, which is not directly associated with the single breasts or specific organs.

In the field of psychosis such dynamics within certain parts of the body were also drawn (e.g., psy_01, such as ellipses representing weight, space, or boundaries; arrows representing forces that can either reinforce the meaning of the ellipses (weight on the shoulders) or be in opposition to them (trying to break out (chest) or to implode (head) in terms of a black hole that absorbs everything; Figure 2). In commenting on their drawings, interviewees specified the temporal occurrence of certain experiences, either explaining how often and in which situations certain sensations occur, or pointing out how one thing can cause or reinforce another. Unlike the field of fboc, the individual experiences of risk in the field of psychosis displayed in the BMs were closely connected to the bodily sensations and symptoms of the diverse variations of psychotic experience, e.g. hearing voices; fear; pain; depersonalisation and derealisation (like in the case of psy_03); or persecutory delusion. The majority of the drawings focused on the head, and more particularly on the forehead or the crown of the head where the brain is situated. The interviewees' explanations accompanying their drawings in some cas-

es underscored this focus, e.g. in terms of the explicit mention that 'it is actually the head' (psy_02). Concerning the quality of the experience, some of the participants particularly referred to the feeling of being 'trapped in one's head' or 'trapped by one's thoughts' (psy_01; psy_07). The risk of psychosis is perceived as something mainly happening inside the head; however, also as influenced by factors outside the body, and by an interplay between bodily areas. The drawings were used to express how parts of the body were interconnected or communicating with each other, or also to visualise emotions and dynamics, for example opposite forces struggling inside one's body or interactions between the inner and outer world. One participant (psy_07) drew a dense jotting or 'tousled' scrawl in the crown of the head and a heart being surrounded by a circle with sharp triangles pricking or puncturing it (barbed wire); head and heart being connected by a two-sided arrow. The interviewee pointed out a mutual influence between the confusion in his head and a feeling of having a barbed wire around his heart. 'Health' would mean that the axis between head and heart is in balance and calm can occur.

The BMs in the field of early-onset dementia, drawn by students in the context of medical edu-

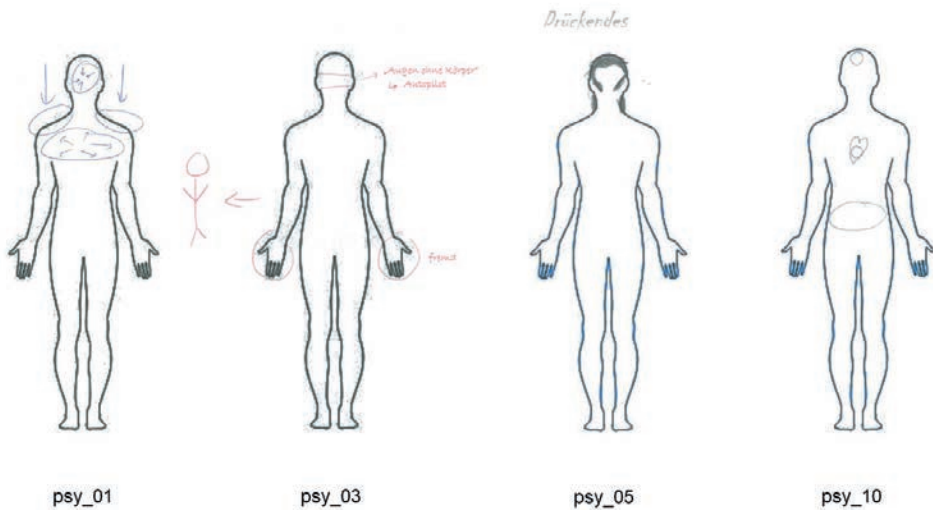


Fig. 2 Selected body maps from the field of increased risk of psychosis.

cation, revealed individual and collective experiences and sensations associated with risk (Figure 3); mainly, these can be read as symptoms of fear (e.g. widened eyes, trembling knees, a tormented stomach), burden (e.g. weights), uncertainty (question marks), the incapability to see clearly (e.g. clouds, storm), sad mood or depression (e.g. black clouds or rain, broken heart), helplessness (feeling trapped in chains), and loss of control (e.g. standing on a slippery ground or losing ground under one's feet). In this field, students interpreted the risk primarily based on the severity of the medical prognosis, which was displayed by symbols of bodily and social experiences associated with negative medical future scenarios.

In her recent study on women's worlds in Banaras, GUPTA (2022: 336–344) examines risk as a feminist keyword that “presents women as active technicians of their own lives”. Borrowing on this conception we suggest looking at disease risks also as enabling phenomena. The analysis of the BMs included in the current study supported this perspective on risk.

In the analysed BMs in the case of fboc, risk was depicted (1) solely inside the body following the medical terms on risk, (2) both in- and outside the body, emphasising the mental dimension

of knowing as well as social factors that may impact risk and (3) solely outside the body, whereby risk is seen as non-existent (due to risk-reducing surgery). All three understandings of risk reveal its enabling role - risk was depicted as a function of individual's actions. In some cases to take action on risk was associated with achieving a balance between being aware and excessive concern, whereby excessive concern is depicted as driven by outer factors and not coming from the body's inside (fboc_01, fboc_02). In other cases the risk is clearly located into the respective organs (breasts, ovaries and womb) and there is no clear mental or outer dimension. In these cases agency is closely related to certain medical decisions like surgery (fboc_03, fboc_08, fboc_10). In one case risk is solely depicted as outside the body and its role is explained as a warning system that activates from time to time (fboc_04). In this case agency consists of the ability to be able to pay attention to this warning system in the right time.

In contrast to the other fields, only in one BM a question mark was used in the field of psychosis (psy_04). Instead, more symbols visualising insight (such as arrows illustrating connections or dynamics) were employed. This can be interpreted in the sense that knowing about the risk

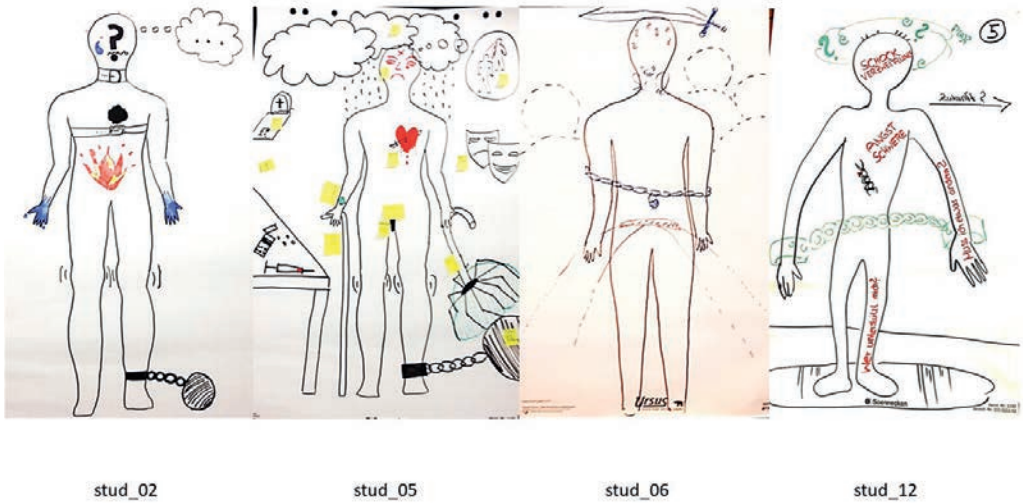


Fig. 3 Selected body maps from the field of increased risk of early-onset dementia.

of psychosis is more strongly associated with understanding and certainty concerning a vague situation rather than uncertainty. When commenting on their drawings, participants also referred to their risk of psychosis as a chance, as a means of becoming aware, of finding oneself, of re-integration of parts of oneself and of oneself into society (e.g. psy_09).

The BMs in the field of early-onset dementia drawn by students hardly appear to show risk as an enabling phenomenon; only in one of the BMs (psy_12) elements can be found that refer to the potential perspectives of the situation. In contrast to the other BMs, despite symbols and writings indicating negative feelings and uncertainty (question marks) or confusion, the composition of the entire picture has something light, agile, which may be reinforced by the dynamic posture of the person, looking as if they are walking or at least in some preparation for movement. Also the writing next to the left shoulder (Zukunft?) with the arrow directed to the right may suggest that there is hope or something can be done. This is reinforced by the writings ‘Muss ich etwas ändern?’ in one arm and ‘Wer unterstützt mich?’ in one leg. However, the arrow could also indicate determinism and hopelessness (Ausweglosigkeit) since this is

where the person will have to go, without any uncertainty. Or it might indicate that it is uncertain at all whether there will be a future for the person. Next to the uncertain and threatening components, this BM entails the idea of risk as a turning point or a trigger for transition in one’s life, and the image of the person at risk as an active, reflective and responsible individual who needs to make decisions on his or her future.

Social anthropologist ÅSA BOHOLM (2015) emphasised the importance of looking at identity and not solely at cultures while doing research on risk. She suggested a context-based theory on risk (BOHOLM 2003: 159–178) and claimed to look at the “situated risks”. The analysis of the BMs in this study demonstrated their value as a source of understanding better the situatedness of disease risks for a certain individual, in a specific situation, at a certain point of time.

In the case of fboc, such situatedness was represented by the different sources of knowledge on risk and the possible disease, which were depicted and made visible through participant’s testimony. In the case of one participant, e.g. the drawing displayed three different sources of knowledge on risk: (1) medical knowledge (use of medical terms) about certain medication and the associated side

effects as well as the function of the different organs, (2) symbolic knowledge on the cultural concepts of femininity and fertility and their “danger” of causing cancer and (3) embodiment of risk as the ability to hear and feel the own body and to recognize the interrelation of body and mind (fboc_01). In another case, a participant referred to normality as a state of happiness and well-being and reaching normality (as the state before cancer) as essential for the restoration of identity after surviving cancer (fboc_07).

The BMs in the field of psychosis also visualise attributes concerning identity. For example, one participant put a strong emphasis on his head in his drawing (psy_07) and described himself as an analytical type (German: *Kopfmensch*). Other participants referred to the idea of people with mental illness as being particularly blessed or gifted with special capacities. For example, one participant described ‘being different’ as a moral resource; in contrast to people with high cognitive and social skills, persons with ‘that particular disposition’ were not as aware of their own appeal and therefore not able to manipulate others (psy_09). One participant used the metaphor of ‘my halo’ (psy_02) to describe her drawing pointing to the dizziness, confusion and thoughts inside and outside her head; looking into the iconographic meaning of a halo, it has been used in images of saints or of rulers (BRITANNICA: undated). Another participant (psy_03) talked about her derealisation and depersonalisation; in the comments on her BM, a high, nearly literal convergence can be found with the symptoms of these experiences mentioned e.g. in Wikipedia. This can also be interpreted in the sense that encyclopaedic knowledge about one’s risk can serve as a resource for ‘legitimation’ and identity.

The BMs in the field of early-onset dementia drawn by medical students bespeak the pervasiveness of risk for a person’s identity; it could even be said that the identity vanishes behind the risk or the person’s identity is reduced to his or her ‘at-risk state’. For example this becomes evident by the way students depicted the faces on their BMs. In many cases, extensive symbols were drawn in place of faces such as huge question marks, thunderstorms with rain, or writings. If faces (or elements thereof) were drawn, the face looked sad, crying (stud_05, stud_14), terrified (stud_08)

or somehow depersonalised (stud_01, stud_10, stud_13). In the case of stud_01, the face is even crossed out which may be read as a symbol for striking through a person’s identity. This may partly be explained by the fact that students depicted the situation when the person first comes to know about their risk which is characterised by shock. This is a snapshot in time compared to the BMs by our interviewees who had already been dealing with their risk for a longer time and with the opportunity to integrate the risk into their biographical narrative.

b) Narratives of risk, mirroring society’s symbolic order and boundaries

The high value of certainty in nowadays’ industrial societies has led to the development of technologies and scientific methods that claim to assess risks in a rational way. Nevertheless, such methods and technologies have intrinsic limitations, since they cannot answer the question “why a particular individual suffered a particular misfortune at a particular moment in time. Nor can they change uncertainty into absolute certainty in the same way as magic” (ALASZEWSKI 2018: 21–41). In *Purity and Danger*, DOUGLAS (1966) examined risk as a product of symbolic order and cultural classification work, providing evidence that risk cannot be reduced neither to pure objectivity (natural deficits) nor to pure subjectivity (psychology of an individual). Her argument is to look at risk as a symbolic system that is taken for granted by the individuals using these symbolic classifications. The depictions of risk in the BMs analysed in this study may serve as a good starting point to look at these symbolic taxonomies.

Interestingly, in the case of fboc, the BMs depicted primarily the two extreme risk dimensions – pure objectivity, in this case guaranteed by medical knowledge and genetic testing as well as pure subjectivity, whereby the psychological dimension of risk (as enabling phenomenon) is emphasised. Some participants accentuated on the objectivity of risk employing a medical explanation to describe their drawing (fboc_08), or explicitly mentioned that they decided against including the head in the drawing, revealing certain anticipated expectations on part of the interviewer or also to societal discourses about dealing with risk

and disease (fboc_10). Contrastingly, other participants accentuated on the subjective and psychological dimension of risk as also related to the soul (fboc_02). Similar to the findings by SKOP (2016: 29-43) we also found across-group commonalities in the use of specific symbols to depict certain body parts or risk perceptions. This speaks for a dimension of universality of certain images and metaphors (SKOP 2016: 41). In the case of fboc, participants used circles to mark the body parts affected by risk. Circles may be associated with female roundness and the shape of the depicted body parts (breasts, belly, knees). In the same vein, the risk for the breasts and the ovaries is depicted in some BM by small crosses, which may be interpreted as less emotional than a heart e.g., used to symbolise the womb. Crosses may be also interpreted as a sign for crossing out, erasing, for something that is missing (fboc_03). Such symbolic meaning may also be related to shared meanings on femininity: e.g. the “danger” of femininity in medicine (fboc_01) and medicalisation of the female body (NISHA 2022: 25-40). The use of arrows may depict the sharpness and “danger” of the knowing about the risk and its burden (fboc_01). The symbolic system of normality is also made visible through the BMs and the respective explanations of the drawings. For example, it is considered as a norm that people follow the medical recommendation (undergoing regular check-ups etc.) (fboc_08) and the normal life is considered the one without cancer and with minimised risk (fboc_07).

The symbols and respective explanations in the BMs in the field of psychosis also showed attributions of characteristics or ‘roles’ of certain parts of the body in their mutual interplay, referring to the duality of head and heart or belly. For example, the head was attributed the role of ‘authority’, analytic force, rational control, ‘switching on’ or ‘intervening / stepping in’ (German: *sich einschalten*; e.g. psy_04, psy_07), while feelings were located in the heart or in the belly, associated with loss of control, irrational, intuitive forces (e.g. psy_04). Moreover, the drawings strongly visualised the discourse of mental illness as being located inside the head and mental problems being confined to the head. Moreover, some BMs illustrated the discourse about risk as being located inside the body and impacted by outside factors (e.g. psy_02, psy_06).

The BMs in the field of early-onset dementia drawn by medical students pointed to symbolic orders shaped by the power of definition of medicine and – closely connected to this – the duality between ‘ratio’ and analytic knowledge versus feelings and emotional knowledge. Concerning the power of definition of medicine, in many BMs the determinism of medical diagnosis becomes evident: from one moment to another, a person is trapped and his or her identity is determined by medical reality (e.g. in stud_02, there is a huge question mark instead of a face). The medical power of definition also affects people’s lifetime (stud_04), their freedom (being trapped, symbolised by chains), their ability to think clearly, their dignity (e.g. stud_04 – the person looks humiliated, unmasked, naked). In one BM (stud_05), the total helplessness and disability in the face of a medical diagnosis becomes visible: even the means and resources that the person might want to use to cope with the situation are made unsuitable or ineffectual as symbolised by the broken umbrella. One picture (stud_07) did actually not contain a BM but only the writing ‘Die weite Leere’. This could be interpreted in a way that with the knowledge about one’s risk, everything else in life is wiped away. The duality between ratio and feelings can be seen as closely related to the medical power of definition, since risk-related knowledge is considered as ‘factual’, based on analytical evidence, while the person’s reaction is considered as emotional and uncontrolled. For example, stud_14 visualised discourses about patient roles in medical conversation, depicting information as raining down on the person whose hands are trapped so that he or she is helpless, passive, lacking agency, having to endure his or her destiny as a person at risk.

In her work, DOUGLAS (1966) pointed out that boundaries are crucial to the identification of risk. Common for most societies are boundaries of the body and boundaries that mark different social groups. Body and social group are often symbolically linked in terms of risk identifications. In the case of disease risks such boundaries are related to the body as risk carrier and the boundary between the culture of medicine and the culture of non-medicine (NAPIER *et al.* 2014) wherein different classifications of risky and non-risky factors and behaviour build the respective symbolic

order. On a methodological level the BM can be also seen as a boundary itself between the presence and the future in terms of risk. In one case in the field of fboc, e.g. a participant perceived the BM as an unwished intervention in the course of life, which may turn risk into a disease. In this case, drawing on a BM was perceived as a taboo since the abstractness of the risk was preferred compared with its clear visualisation (fboc_05). In another case the degree of medical/scientific knowledge was seen as a boundary between objective and non-objective risks. In the case of fboc_06, non-sufficient medical knowledge is interpreted as a liminal stage that would be passed once enough knowledge will be generated. This is the explanation why the risk of pancreas cancer is marked by a question mark instead of an exclamation mark as in the case of the breast cancer risk (fboc_06). A third boundary in the case of fboc is marked by the possibility of action to minimise risks. On one BM, e.g., the drawing of the breasts (crossed lines) together with the writing 'Risk: 0' appeared like an achievement, something you can be proud of or at least relieved about – while the two red crosses seem like dangers lying in wait, lurking and still not leaving the person in peace (fboc_09).

The BMs and the accompanying explanations in the field of psychosis can be interpreted in the context of the literature concerning the boundaries between 'normality' and 'insanity' (LORKE, SCHWEGLER & JÜNGER 2021). From a critical anti-psychiatric stance, it is argued that these boundaries are rather fluid than deterministic (DÖRNER *et al.* 2019); this argument is a strong motive in scientific literature as well as in arts (e.g. novels or movies such as 'Repulsion' by ROMAN POLANSKI, or 'An angel at my table' by JANET FRAME). One participant (psy_09) explicitly referred to this argument by stating that a person with a seemingly stable life can all of a sudden lose his or her mind if several factors come together. From a systemic perspective, a person with mental illness, instead of being labelled as 'other' (assuming a sharp boundary between 'normal' and 'insane') could be considered as integral part of the system in terms of a 'symptom carrier' for problematic phenomena in a family or in an industrialised, capitalist society. For example, in the case of depersonalisation (psy_03) the feeling of being dissociated from

one's body or reality could be seen as an extreme form of the detachment that may be considered as common for many people in a mechanised, digitalised world characterised by an overloaded everyday life.

The BMs drawn by medical students gave evidence of the dualistic and deterministic boundaries between 'healthy' and 'at risk', between 'health' and 'disease'. It is striking how many of the BMs contained symbols of being trapped and captivated, such as chains around the body with a padlock (e.g. stud_06, stud_08), chains around the arms with handcuffs (stud_04, stud_12), or a shackle (stud_02, stud_05). This gives the impression that the information concerning an increased health risk is like an imprisonment or a bane, and people have to find strategies to free themselves out of this situation. It also points to the power of medical prediction and diagnostics to attribute or even impose roles, feelings, and realities upon people based on professional knowledge. One BM (stud_06) was particularly interesting in terms of the roles and boundaries related to disease risk: in this BM, there were three human silhouettes drawn in dashed lines standing behind the person; risk, amongst other symbols, was visualised by a pending sword of Damocles above the person's head. The silhouettes could point to the relational / familial dimension of genetic risk. At the same time, they remind of the pictograms with human silhouettes to illustrate the risk e.g. in fact boxes (1 out of 10 or 23 out of 100) and could hence refer to the different possible outcomes of the risk prognosis. In this regard, the persons in the background could also be interpreted as silent bystanders, as trying to hide away, being silent, trying not to attract attention since they could be the next to be affected – with the threat of impending risk for everyone, you can never be sure whether you might be the next one. Another BM (stud_05) also referred to boundaries between the person at risk and other people, visualised by a smiling and a sad theatre mask. These may symbolise that a person is hiding their feelings and faking a smile while crying inside. Here, discourses of coping with disease in society become evident – feeling lonely with the new reality of being affected, and hiding one's feelings and pretending good mood while being sad.

c) Risk perceptions and coping strategies as purification practices

The analysis of the BMs in this study revealed the process of how individuals reflect on their risk perceptions and link them to certain coping strategies. The majority of BMs does not just depict the disease risk out of and within the body but moreover tells the story of the individuals' way to handle the risk. In the case of fboc, e.g., one participant displayed risk as situated lightly above the shoulder like an angel and a devil performing a navigating function and being an advice-giver (fboc_04).

Other than in the field of fboc, the BMs in the field of psychosis showed less emphasis on the idea of risk and less focus on the future. Instead, bodily sensations and connections of experiences of the past or present are expressed by the drawings. The accompanying explanations indicated processes of meaning-making, causal explanations of experiences, and reconstruction of determining factors that may either aggravate or help to ameliorate one's situation. The interviewees' comments described risk as variable in time, as contingent, as depending on one's life situation – and as a balance of rational thinking, feeling and intuition. They also revealed a reflection concerning the attribution of their experiences to internal or external forces, often describing risk as a complex happening and interaction between the inner and the outer world, including different parts of the body. For example, one participant (psy_05) who has drawn a sort of helmet and written the word 'pressing' above his head, describes risk as a variable of too much distress over a longer time. He appears to struggle with both localising the source of his pressure and distress, and also interpreting the function of the helmet. His accompanying explanation illustrates this struggle for meaning between forces from outside ('someone pushing onto my face' / 'someone puts me a helmet on') and forces from inside ('perhaps it is my own head that puts all this on'); and between protection (a mask that can cushion things) and un-comfortableness (pressing, boiling).

In the case of early-onset dementia, risk was displayed as an inevitable event that completely changes individual's present and future, disrupting the course of their life and identity. Due to the

high certainty of the risk prognosis and the devastating effect of the illness on personality and well-being, risk perceptions were depicted based on shared cultural beliefs associated with risk, disease and the human body. Thereby, the disease is displayed mainly using representations of the social dimensions of the disease as well as the psychological experience of the fear of death. Since the participants were medical students, in some of the BM, the medical power of definition and the determinism of the medical diagnosis were displayed (stud_02, stud_04). The perceptions of risk in the field of dementia are displayed from the perspective of the individual as a "patient" whereby the medical diagnosis dominated the individual's entire life (stud_05, stud_12).

Turning the uncertainty into certainty is related to the crossing of boundaries on risk. In the case of health risks, such boundaries are placed on the body and in the culture of medicine. Following the classic study of rites of passage of VAN GENNEP (1960), who saw society as a house with rooms and hallways, where the passage from one to another is considered dangerous, the danger lies primarily in the liminal stages "inbetween" (TURNER 1964: 4–20), where the pure and the impure blend. In order to ensure protection and enable the transition a ritual or a purification practice is needed; a practice that turns the disorder, abnormality and otherness into normality and safety (DOUGLAS 1966). In this sense, it may be worth to look at this process from TURNER'S perspective of liminality (1964) outlining different forms of *becoming*. Such perspective may seem provoking or constructed on the one hand, but it may also provide valuable insights in the process of translating risk meanings into illness, life experiences and identity.

Purification practices can also be considered in the context of sociocultural illness narratives such as the "restitution narrative" (WONG & KING 2008: 580), implying a normative view of bodily integrity as normal state that needs to be maintained and restored. Likewise, communication regarding risk prevention by Human Papilloma Virus (HPV) vaccination is characterised by metaphors of protection of a pure, integer, in a way childlike and immaculate original state of health (JÜNGER 2024: 157).

The BMs in the field of fboc displayed two different purification practices: a physical one (in

terms of preventive surgery or preservation of the body through healthy way of life) and a psychological one related to the development of narratives that make risk controllable through mental resilience. In one case, the participant described surgery as a way to get control over risk, claiming that the changes in her body as a result of it did not affect her self-image (fboc_07). In this case the surgery as purification practice restored the cultural definition of normality. Similarly, in another case, the controlled risk (minimised after surgery) was depicted on the BM even though the participant did not consider it as any longer existing (fboc_08). In other cases, emphasis was made on the importance of one's own way of coping and dealing with risk (fboc_01). The risk of cancer was depicted as related to an individual's self-perception and coping strategy whereby the strong performative power of thoughts is accentuated, causing e.g. physical discomfort or affecting choice of clothes (fboc_02, fboc_07). Dissociating oneself from anticipated expectations and the knowing about the risk is also a form of purification practice (fboc_10).

In the field of psychosis, different coping strategies and purification practices become evident in the interviewees' reflections on their BMs. For example, some participants focus on the disruptive forces, referring to the bursting nature of their experience that metaphorically reminds of a volcano with hot lava blubbering under the surface before breaking out. This outburst also appears to entail a relief, the chance of healing, and a transition in terms of becoming whole. For example, psy_01 talks about a 'burden on his shoulders' and 'something radiating from his chest, crying that it wants to get out, that something needs to burst outside of him, particularly in low times'.

In some accounts, the adjustable nature of risk as a function of lifestyle becomes visible. For example, the emphasis on the relevance of a balance between head, heart, and belly reveals a sense of agency concerning risk as something that can be modulated by one's own attitude and behaviour. Coping and purification can here be achieved by modifying one's lifestyle in a more 'healthy' or more 'risky' way, for example, by maintaining structure, balance, and equilibrium in one's everyday life, paying attention to a 'healthy diet' and thinking positively. For instance, psy_08 used

the metaphor of a slider on a numerical scale to indicate the current degree of risk that can move towards lower and higher risk depending on his current lifestyle. Also psy_10 comments on the function of equilibrium for the modulation of risk, for example with respect to a healthy diet. These explanations also refer to discourses of (re-)gaining control by self-regulation and self-discipline, and by making healthy and rational choices and learning strategies and techniques to calm down one's distress. Since contact with our interviewees was established by a centre for early detection and intervention and many of them had attended the centre's day care unit with a focus on cognitive behavioural therapy (CBT), it can be assumed that their perceptions of risk and disease are shaped by the concepts of this therapeutic approach. Metaphors such as 'drifting' or 'being off track' as a way of losing control, and 'coming down' or 'bringing oneself down' when the head 'switches on' or 'intervenes' (e.g. psy_05; psy_07; psy_08) also bespeak this idea of cognition taking over, sorting out the situation, and helping to regulate emotional escalation. However, the interviewees' comments on their drawings also reveal the ambivalence between agency and control in terms of the visible effects of one's actions on the one hand, and a perceived disproportion between one's efforts and discipline (working hard, renouncing) and only small effects on the other hand. A contrast between the 'linear' and logical explanation models of CBT and a perceived complexity and contingency in terms of not being able to explain everything becomes evident. Also finding a balance between the comforting, positive effect and a negative impact of certain actions is described as challenging; for example with regard to smoking pot as a self-medication and a relaxation that enables to perform in everyday life, and as a risk factor for psychosis (psy_07); or with respect to an abundance of experience that may imply positive impressions (eustress) and at the same time lead to time pressure and distress (psy_08). The metaphor of a 'halo' (psy_02) could also be associated with a purification practice, maybe to contrast inner feelings of inadequacy, or in terms of symbolically purifying these inner feelings.

The BMs in the field of early-onset dementia offer another picture of handling risk. Since risk is perceived as inevitable, the danger of the lim-

inal space is associated with the emotional aspect of knowing that something devastating and inevitable will happen at some point in future without being able to change the course of the events. The agency of the individual is depicted as a hopeless effort to get control over the chaos caused by the knowing about the risk (like the broken umbrella in stud_05 or the chains and belts in stud_04, stud_08, stud_12 and stud_13). Nonetheless, one BM represents also an image of the person at risk of dementia as an active, reflective and responsible individual who needs to make decisions on their future (stud_12). The life with knowledge about an inevitable risk before disease occurrence is perceived as the liminal stage that needs to be overcome and the decisions on how to live this life as a purification practice in order to “guarantee” orderly life when entering the state of illness.

Methodological and ethical reflection

The findings in this article may provide deeper insights in the meaning-making of risk in predictive medicine from the perspective of those considered to be at risk, and also in the use of body maps in research and teaching. Nevertheless, the findings demand a thorough reflection on both methodology and interpretation of the data. In general, the article faces the challenge of providing a secondary analysis of the body maps without coupling it with a direct analysis of participants’ narrative interviews on risk (already published in HARZHEIM *et al.* 2020; LORKE, SCHWEGLER & JÜNGER 2021; LORKE *et al.* 2021; HARZHEIM *et al.* 2023). This was an obstacle the authors faced due to the pre-defined structure of the project; for future research we will recommend triangulating all types of data in the analysis and publication.

The use of body maps as research tool

First and foremost, the rationale for the use of BMs should be carefully argued – in which situations and for which research questions can this method be considered appropriate? In the case of our study, this implies a reflection on the potential of the chosen methodology for knowledge generation concerning embodied risk. From an epistemological point of view, BMs can be considered as integrating body, mind, and social context (SKOP

2016: 29-43) and therefore as particularly suitable to explore individual and collective representations concerning a certain health-related condition or risk.

Moreover, the method needs to be designed in a manner that is suitable in the context of the respective research purpose. In our study, we needed to choose a way to integrate it into our interviews without causing participants additional effort or demanding more time from them while still inviting them to share with us their visual representations of risk. We therefore decided to use a standardised silhouette printed on an A4-sheet and to ask participants spontaneously towards the end of each interview to perform the exercise. From a methodological point of view, this has several implications. First, participants had only little time to unfold their story on the BM or even develop it further over several sessions as in other studies. This may have restricted the richness of data; for example, SKOP (2016: 29-43) reported that many participants did not complete the self-portrait of their faces until the fifth session which suggests that some layers of introspection may need more time to be accessible to awareness and expression. Second, we used a small standardised silhouette instead of people’s own personalised life-size body sketch. The template can be considered as gender-neutral, but at the same time also abstract and not fitting to individual particularities. VAN RANTWIJK (2021) emphasised the effects of different representations of the bodily figure, such as size, shape, gender-specificity, only front view or also rear view of the body, or 3D-BMs. Indeed, in our study only in one instance the rear view of the body was used, while in all other cases either a clear front view (indicated by a face) or an unclear perspective was observed. Also the types of material provided to work on the map are considered important (VAN RANTWIJK 2021); in our study, little material was available to participants, restricting the creative process to drawings with pens in one or two colours. However, despite these restricted means, participants used these to express and document the quality of their experience, e.g. by drawing several circles instead of a single line; making a ‘tousled scrawl’; or putting pressure on the pen to indicate an emphasis or point to the impact of a particular experience.

From an ethical point of view, body-map storytelling may be considered as an appropriate method when applied in a caring and respectful manner. This includes informed consent in the form of a process rather than an event, particularly if body mapping extends over a longer period with several sessions (GASTALDO *et al.* 2012). Also, confidentiality needs to be ensured; it is therefore important to reproduce BMs or alter information that might potentially identify the participant, such as handwritten notes. For participants' protection, a safe space needs to be created and potential risks of the body mapping process deserve reflection. For example, in our study it became apparent that for one participant (psy_05), the interview and the process of drawing the BM were evoking the same distressing feelings that were also associated with his symptoms. A phone call sometime after the interview could clarify that the participant was fine and did not feel burdened by the interview. However, it is important to anticipate emotional triggers and the potential of releasing repressed traumatic experiences while dealing with embodied phenomena. Another risk that needs to be considered is related to the constructivist nature of the BM as a means to re-construct a person's health-related reality. Particularly in the context of risk, drawing risk-related symbols into a BM can be perceived as evoking one's fate like in a voodoo doll or a self-fulfilling prophecy (e.g. one participant (fboc_05) refused drawing the map since this was perceived as unduly interfering with fate). On the other hand, we also observed that body mapping was seen as a source of self-reflection; while drawing and commenting and gaining introspection into one's bodily sensations, many of our interviewees were able to engage in a process of meaning-making with regard to certain dynamics and connections.

Last but not least, the process of body-map storytelling also poses special demands on the researcher in order to ensure that participants – and they themselves – feel emotionally safe (SKOP 2016: 29–43). During the research process, we therefore regularly took some time within our team for reflection, and to provide mutual feedback and support.

In summary, body-map storytelling can be a source for rich data on people's experiences as individuals and as a collective (GASTALDO *et al.* 2012;

LYS *et al.* 2018: 1185–1198), when carefully planning the study in terms of a justification for the use of BMs, well-founded methodological decisions, and sensitive ethical considerations.

The use of body maps in teaching

The application of BMs in teaching context entails various methodological and ethical dimensions that need to be reflected on: the context of research/application, the researcher's/lecturer's role in the process, the level of participants' involvement and group dynamic, the interpretation and publication of the data.

The use of BMs in the context of medical education has certainly affected the tone of the BMs included in this study – the mood evoked through the images and words used by participants to express their positive or negative healthcare experiences (SKOP 2016: 40). On the one hand, the occupation with risk in a study-related environment (the medical faculty) in the context of seminar on medical ethics may have led to an overemphasis on the medical definitions of risk and to a neglecting of individual and social dimensions that may be individually relevant for each participant. In the current project, we decided to adjust the methodology in order to create a safe space for the particular group (following the example by SKOP 2016: 29–43 who assured her material was scent-free because many people with fibromyalgia have chemical sensitivities). We conceptualised the risk case as learning material, and the creation of the BMs as a group work (role play). The clear rules of the role play and the scripted risk experience helped to create common responsibilities in order to establish group cohesion, trust, and rapport. Nevertheless, even using a scripted risk situation, we could not fully eliminate the risk of emotional triggers in some individuals and the potential of releasing repressed traumatic experiences. That is why we strongly encourage developing strategies to maximise emotional safety in group situations and consider involving at least two researchers in the body mapping process. The impact of teachers (GASTALDO *et al.* 2012: 14) on the body mapping process also needs to be reflected upon. We were continuously sensitive to potential discomfort during the mapping process and modified the way we supported the groups during the exercise

accordingly (e.g. provided more context to our research or repeated the guidelines for performing the body mapping). We as teachers were also emotionally affected by participants' experiences with risk and constantly questioned the different risk definitions (e.g. often thinking about symbols/images in other contexts). In order to reflect on these experiences we established regular "formal debriefing meetings" throughout the project to mitigate any concerns caused by the body mapping process and help develop useful strategies (GASTALDO *et al.* 2012: 14). This step was also important during the phase of analysis, since it was necessary to include existing knowledge into the analysis and make it visible. One significant limitation in the context of the BMs used in a teaching context was that we were not able to take detailed notes during the process of body mapping. Since the meaning of a BM may be "fully understood only by the accompanying story and experience of its creator" (COETZEE *et al.* 2019: 1237–1254) the process of analysis was complicated because we needed to rely on no direct accounts of the participants, but only on the researchers' notes and memory. This challenged the movement from a descriptive to a critical interpretation of the mapped stories (GASTALDO *et al.* 2012: 18).

In spite of all limitations, we experienced the use of BMs in teaching as a valuable resource in the following three dimensions. (1) BMs can contribute to a more diversity-sensible teaching environment offering access to different types of knowledge (technical, cultural or experiential). (2) BMs can contribute to the development of new teaching approaches in medical education that may increase empathy since there is evidence that integrating arts and humanities in medical education may enable the flowering of empathy (LAUGHEY *et al.* 2021: 1941–1950) and stimulate of individuals cognitive capacities (ROBERTS 2021: 1075). (3) BMs in teaching may draw students' attention to the cultural, social and psychological aspects of risk (following the concept that the health-illness process is primarily social and cultural, into which the biological and psychological aspects are inserted (QUINTERO 2014)) in order to respond to current and future challenges posed by ongoing technical progress in biomedicine.

Conclusion

The BMs in the context of this study revealed their role as a medium for meaning-making and (co-) construction of risk in science, society and individual lifeworld. Drawing on our findings and experiences, we can conclude that the use of BMs in research and teaching offered a great potential as a means of reflecting on and understanding embodied health risks. BMs on risk revealed a plurality of perspectives, lifeworlds and way of meaning-making of risk. Such visual methodologies can help participants pay attention to phenomena in new ways (LYS *et al.* 2018: 1186) and address both individuals' different sources of knowledge as well as their personal emotions on risk, hereby opening up spaces for analysing the situatedness of risk (BOHOLM 2015). In a way, the body mapping allowed participants to 'unpack' the stylised human silhouettes in infographics on risk statistics that are used as anonymous placeholders for probabilities in risk communication, unfolding their personal story of risk.

The analysis of the BMs collected for this study showed risk as a product of individual experiences, enabling phenomenon and related to identity and puts the role of risk in individuals' personal and social contexts up for discussion. The analysed BMs also demonstrated that risk was constructed through narratives, which mirror society's symbolic order and boundaries. The ways individuals and societies cope with risk may be seen as purification practices that help to re-establish the social order of normality and abnormality, order and chaos, purity and dirt.

The integration of BMs into research practices may open up spaces for the interrelation between body, risk and society offering corner stones for the investigation of risk situatedness. In teaching, BMs can contribute to the development of new teaching approaches in medical education that enable the flowering of empathy and resilience (LAUGHEY *et al.* 2021: 1941–1950) on the one hand and training students' skills in interpreting the social and cultural dimensions of the health-illness process (QUINTERO 2014) on the other hand. In spite of all ethical and methodological limitations of the current project, we experienced the use of BMs as a valuable resource for both research and teaching and therefore encourage further initia-

tives in this field, which is still an area of methodological discovery.

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Visual Embodiments of Bodily Sensations and Their Individual Conditionality

A Visual Phenomenology

BARBARA GRAF

Abstract This paper gives insight into the exploration of perception, visual representation, and mediation of physical symptoms using methods of artistic research. A crucial question is what experiences and languages can serve to re-present the invisible. The cultural and individual context through which perception is first constituted plays an essential role. Bodily sensations are everyday experiences, but become even more explicit through symptoms of illness. Lived experiences are deeply subjective and require a language in order to be conveyed. This investigation is based on self-experienced incidents caused by multiple sclerosis (MS). Many individuals afflicted with MS experience paresthesia due to a signal-transmission disorder in the central nervous system. The symptoms are not perceived as occurring at the actual location of the damaged nerve cells; in addition, there is no external stimulus associated with the sensations. Such sensations include that of socks covering the feet or balls of textile material underneath the feet. This material is perceived as foreign. These illusions seem perfectly real and are irritating. The process of making bodily phenomena visual is preceded by introspection and leads to externalization, these phenomena acquiring, in this process, an additional existence outside the body. The transfer to a sheet of paper can bring relief and help in the process of regaining possession of an alienated body. The drawings are also a means of conveying the invisible to other affected persons, their relatives, and persons in the clinical field. In the process of sensation–perception–representation, a double question arises: What pre-existing images occur during perception and to what extent do the visual representations allow the recipient to begin to comprehend a sensation? Does legibility depend on similarity of experiences and cultural contexts?

Keywords: lived experience – phenomenology – visual embodiment – illness – introspection– externalization

Artistic research approach and context

The artistic exploration of bodily sensations, and the processing of the project,¹ also corresponds to the structure of this text. In addition to the drawings and their accompanying descriptions and reflections, I refer to texts that are an important source for my questions. Most of these texts are from the disciplines of philosophy, medicine, and medical humanities. As a visual artist I do not want to claim to have understood these texts only approximately in their complexity. Rather, this interweaving of different references indicates something of my working approach. If questions arise in the practical artistic work, I try to look at the problem more closely by researching other disciplines. In doing so, new questions are raised—sometimes affirmatively encouraging, but also

contradictory and challenging—and I follow them up in the artistic process.

Point of view and use of terms

This text is written from the first-person perspective, since it is about own lived experiences. Writing in the third-person would contradict the methodological artistic approach, which I also understand as a micro-phenomenology. This concept arises from the neurophenomenological program of FRANCISCO VARELA (cf. VARELA *et al.* 2002) as a study method of lived experiences and was further developed substantially by CLAIRE PETITMENGIN (PETITMENGIN *et al.* 2018: 691ff).

In order not to get entangled in complex terminologies, I would like to say in advance that the use of terms “representation”² and “visualization” can be misleading, as they can be understood quite differently, also depending on the discipline. MICHAEL TAUSSIG would probably replace how I understand representation with the term “mimesis”: “I, however, am taken in by mimesis precisely because, as the sensate skin of the real, it is that moment of knowing which, in steeping itself in its object...” (TAUSSIG 1993: 44). I understand representation as re-presenting in the form of another corporeality through a material existence. The process of drawing responds to a physical sensation and by transferring it to a visual medium it can never correspond; however, it gains a life of its own. The process rather resembles a recording. This depends essentially on the practice of drawing and its materiality. Nevertheless, if there is some kind of correspondence, the drawings may evoke something that is relevant to the lived experience, in its similarity but also difference.

And the term “visualization” is no less complex. Beside visible images, it can also refer to inner—conscious or unconscious—images. Moreover, it is a tricky matter since inner and external images are interdependent. When I use the notion of “visual representations” with respect to my drawings, I understand it as a material embodiment of sensory perception. This is certainly an inadequate simplification and embodiments depend not only on the cultural background of the producer, but also on the context in which the recipient of the drawing interprets and co-forms it. Nonetheless, I would understand the drawings as an articulation of embodied knowledge, which is individually and culturally³ shaped.

Further, I speak of “disease” when it comes to diagnosis and “illness” when it is about the lived experience of the disease. And I call the experienced symptoms “sensations,” even though they cannot be sharply distinguished from “feelings,” because as soon as a physical phenomenon appears and becomes a perception, there is already an emotional interpretation involved.

In lived experiences there is no “pure” sensation

To distinguish sensation from perception clearly seems to be a futile endeavor, since they depend inseparably on each other and are intermingled. To assume that first a stimulus triggers a sensation, which subsequently appears mentally processed as perception, does not correspond to lived experiences since at the very moment a sensation appears at least a part of this perceptual processing has already taken place. It is experienced simultaneously, although physiologically there may be a temporal sequence. To leave a trace in memory, the process may be conscious or unconscious and is recalled in the next experience. This is also relevant to the process of introspection and externalization as it relates to memory, interests, and the production of meaning. In *The Primacy of Perception*, MAURICE MERLEAU-PONTY writes about the process of introspection:

“This is an internal perception, the noting of an event with which I coincide. But reflection is not at all the noting of a fact. It is, rather, an attempt to understand. It is not the passive attitude of a subject who watches himself live but rather the active effort of a subject who grasps the meaning of his experience” (MERLEAU-PONTY 1964 [1946]: 64).

The (un)conspicuous body and alienation

The project of investigating bodily sensations took its departure in the moment when I felt that my body had become another. The reality that we are constantly transforming was irrelevant at that moment. The diagnosis of MS and the accompanying symptoms, also the knowledge that it is not a temporary disease, was drastic. In the relapse that led to the diagnosis, movement limitations were involved as well as incomplete numbness from the soles of the feet to the hips, which later partially remitted. Strange bodily sensations appeared, or rather imposed themselves by their unpleasant or painful character. While some of these resemble everyday incidents, such as the tingling sensation of a hand falling asleep, they are distinguished by their duration and the knowledge that the symptoms may never completely disappear. The body previously taken for granted has become conspicuous, longing for what DREW LEDER calls the “ab-

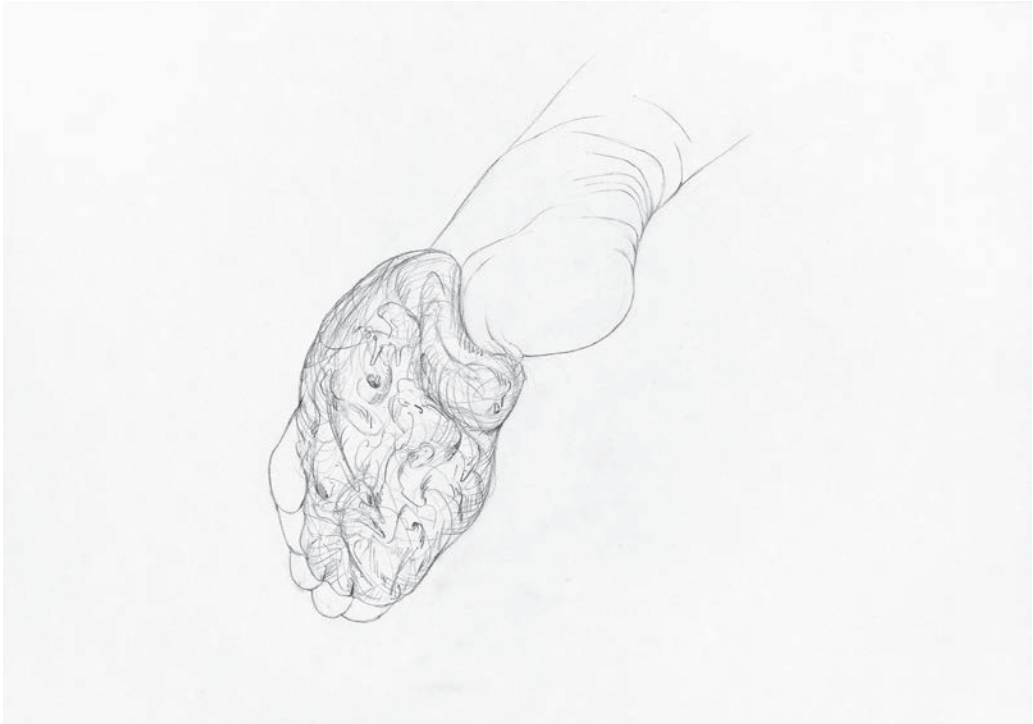


Fig. 1 Barbara Graf, *Drawing 190*, 2017, graphite pencil on paper, 29.7 × 42 cm.

sent body,” the body that is always there, through which we perceive, but is not always the subject of perception. He describes the paradox of simultaneous presence and absence in the following way:

“Insofar as the body tends to disappear when functioning unproblematically, it often seizes our attention most strongly at the time of disfunction; we then experience the body as the very *absence* of a desired or ordinary state, and as a force that stands opposed to the self” (LEDER 1990: 4). The conspicuousness and presence of the body can become evident in pleasant or ecstatic moments, but also in discomforting experiences and the symptoms of illness. This is explored by HAVI CAREL in *Phenomenology of Illness* (2016) and underscores the relevance of phenomenology as a resource for patients, healthcare professionals, and different disciplines such as anthropology and the medical humanities, and focuses on experience and perception: “So far I have suggested that phenomenology can be used to describe illness by focusing on first-person accounts of what it is like to suffer

from a particular condition. On Merleau-Ponty’s view, our experience is first and foremost an embodied experience, an experience of fleshly sensual existence” (ibid. 40).

When strange phenomena suddenly appear as a bodily experience, it means a disruption in sensual existence. For example, due to the nerve disorder, I perceive extra tissue on the sole of my foot (see Fig. 1). I perceive it somehow belongs to me, but at the same time it is a foreign body. This leads to insecurity and the difficulty of understanding one’s own body. CAREL claims “that we have a tacit sense of bodily certainty that only comes to our attention when it is disrupted and replaced by bodily doubt” (ibid. 5). Alienation in relation to one’s own body can be understood in broader terms and not only by the alien sensation of a specific body part. It is not only a disturbed perception of corporeality, rather, it is a disconnectedness. FREDERIK SVENAEUS also uses the term “unhomelikeness”:

“One of two *a priori* structures of existence—not being at home and being at home—wins out over the other: unhomelikeness takes control of

our being-in-the-world. The basic alienness of my being-in-the-world, which in health is always in the process of receding into the background, breaks forth in illness to pervade existence" (SVENAEUS 2000: 93).

These fundamental questions of human existence come to the fore, especially in special life situations, during drastic experiences such as illness. Further, in *The Hermeneutics of Medicine and the Phenomenology of Health*, SVENAEUS refers to SIGMUND FREUD's concept of the "uncanny" ("unheimlich"), which is related to "unhomelike" ("unheimisch") (FREUD 1970 [1919]: 241ff): "Illness is an uncanny (unhomelike) experience since the otherness of the body then presents itself in an obtrusive, merciless way" (SVENAEUS 2000: 111).

The feeling of alienation was strongest in the first period after the diagnosis of the chronic disease; however, this feeling fades into the background when symptoms are less pronounced and other perceptions come to the fore or are partially directed by attention or non-attention. It becomes ordinary that something alien is constantly pres-

ent, like the sensation of fibrous knots being fused with the soles of the feet (see Fig. 2). Now I ask myself to what extent my drawings influence my current perception of sensations? At the beginning of the project, it was my intention to give a visual language to these weird sensations. As an artist who works with textiles frequently and is well trained in drawing, it is almost obvious that such images emerged, as inner visualizations that I only had to bring to a sheet of paper with a pencil. But now, I doubt, if I perceive the physical phenomena simply as they appear, or in the way as I had recorded them before? Do the drawn physical sensations tell me, so to speak, how I should feel? If this were the case, they could also be partially changed by drawing or assigning them differently and would be more flexible than they seem to be at the moment.

Since I have always approached the body as a subject of artistic exploration, it was almost inevitable I make my own body, in its alteration, the subject of investigation. It was not possible for me to simply continue working as before. Visu-



Fig. 2 Barbara Graf, *Drawing 202*, 2019, graphite pencil on paper, 29.7 × 42 cm.



Fig. 3 Barbara Graf, *Drawing 196*, 2018, graphite pencil on paper, 29.7 × 42 cm.

al representations of strange bodily phenomena not only help to investigate the representability of invisible lived experiences, they also engender a coping process, one that leads to accepting, and actively re-appropriating, the alienated body. In relation to the “uncanny” (FREUD’s “*Das Unheimliche*”), this is a strategy to banish the uncanny, even if it remains, as it were, background noise.

Presence and absence

Numbness is an interesting perceptual phenomenon, as it is more than the absence of bodily sensation. Especially when the numbness is not complete, I ask myself if I am comparing this sensation with the state before the sensory disorder or if a new quality of sensation is present, such as a fibrous addition as a reduction of sensitivity (see Fig. 3). Interestingly, the German term for numbness, “*Taubheitsgefühl*,” includes a sensation and not only an absence. The first part of the word “*Taubheit*” (“deafness”) refers to another sense, that of hearing, and the second part to “*Gefühl*”

(“feeling”): a description of an in-between condition of presence and absence.

The situation is different in the case of a complete loss of sensation, in which the alienation is not only more explicit and radical, but results in a complete disconnection, thus even more irritating when the affected body part is visibly present. In his book *A Leg to Stand On*, OLIVER SACKS describes how an accident altered his corporeality. He could no longer move his leg, but above all had no sensations in it and felt alienated because this part of his body no longer belonged to him. What makes his descriptions particularly interesting for narrative medicine is that he was a neurologist and narrates what it means to be a patient, changing positions from neurologist to patient. He writes:

[T]he leg suddenly assumed an eerie character—or, more precisely, if less evocatively, lost all its character—and became a foreign, inconceivable thing, which I looked at, and touched, without any sense whatever of recognition or relation. It was

only then that I gazed at it, and felt, I don't know you, you're not part of me, and, further, I don't know this "thing," it's not part of anything. [...] I had lost the inner image, or representation, of the leg. There was a disturbance, an obliteration, of its representation in the brain—of this part of the "body-image," as neurologists say (SACKS 2020 [1984]: 84f).

Questions of visual representations: touched by textiles

In my artistic exploration and reflection of physical sensations, perception, and depiction, I am concerned with the following questions that can already be affirmed: If I often have a textile perception of paresthesia, is it because, as a visual artist, I regularly work with textiles and have a textile alphabet at my disposal? Or is the everyday experience of being touched by textiles a reason why images of clothing often appear? Does my drawing experience merge with my sensations, and does it, together with other works of art I have seen,

such as LEONARDO DA VINCI's drawings of tempests or RAPHAEL's depictions of hair, serve as my repertoire of pictorial possibilities? This exploration also concerns questions that I cannot yet confirm: Can there be legibility when the recipient's cultural context differs significantly from mine? Can an image convey the feeling of wearing socks (see Fig. 4) or gloves (see Fig. 5) to a person who never wears them? What can my drawings of bodily phenomena convey when similar experiences on the part of the recipient cannot be assumed?

Verbal and visual recordings

During my research, I noticed that visual artists and other people living with MS rarely visualize physical symptoms, although some do refer to their illness through art. It is more common in verbal formulations, and emotional uncertainty and anxiety occupy a larger place in literary expressions than a detailed description of physical sensations. For example, in *The Journal of a Disappointed Man*, writer W.N.P. BARBELLION describes



Fig. 4 Barbara Graf, *Drawing 193*, 2018, graphite pencil on paper, 29.7 × 42 cm.

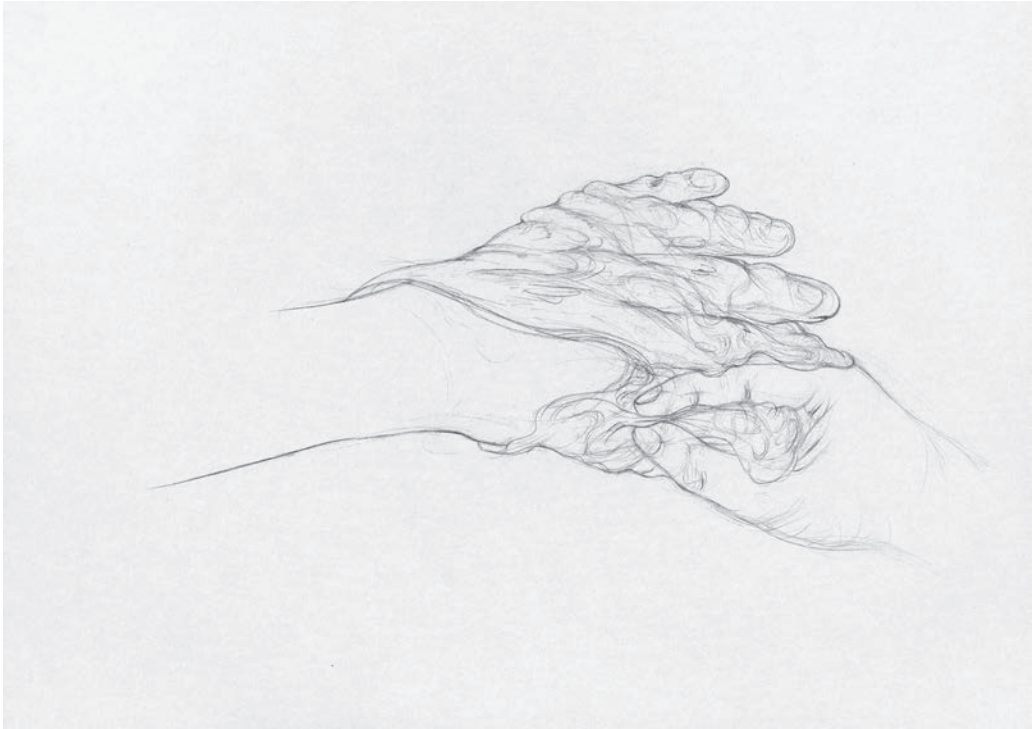


Fig. 5 Barbara Graf, *Drawing 218*, 2019, graphite pencil on paper, 29.7 × 42 cm.

his life struggles, the bodily uncertainty and unclear diagnosis, but also bodily symptoms:

My nerves are giving way under the strain[.] One leg (the left) drags abominably. [...] The numbness in my right hand is getting very trying... [...] “I’ve a tingling in my right hand,” I said, “that drives me nearly silly” (BARBELLION 2017 [1919]: 251ff).

According to the descriptions of the physical phenomena, he had a progressive form of MS. But the detailed diary tells more about his life circumstances and disappointments and he had left the text passages of the diagnosis blank. Furthermore, the term “MS” did not become established until the 1950s. This chronic disease had previously been named by numerous different descriptions. In *Multiple Sclerosis: The History of a Disease*, T. JOCKS MURRAY writes that in most early names “sclerosis” was part of the terminology (MURRAY 2005: 7f).

Early symptoms of MS are often sensory disorders: different types of paresthesia, such as numbness, hypersensitivity, sensation of pain, tingling,

itching, pins and needles, burning, altered sensation of temperature, feeling of largeness, banding (band-like) (see Fig. 6), tightness, or Lhermitte’s sign (electric sensation). Medical professionals name these symptoms based on patients’ experiences. But how to think of the phenomena as an experience and what does it actually feel like?

Affected individuals often describe the strange perceived phenomena with narrative comparisons, for instance: socks rolled up under the feet, towel-like sensation over feet and legs, cotton balls underneath the feet or between the toes, extra pads on the soles of the feet, and many other phenomena related to textile materials (see Fig. 7).

MS groups on social media, where affected individuals share their experiences, are a good source of verbal formulations of the phenomena. Normally, when someone posts describing a phenomenon, there are direct responses sharing similar experiences. So far, however, I have not discovered any images of visually recorded symptoms. MS includes many other symptoms than

sensory disorders. And not every person living with MS is affected by them, or not to the same intensity, or may experience other, more severe, symptoms such as limitations or loss of mobility. My project focuses on the depiction of irritating and disturbing sensory disorders. Fibrous layers, that seem to grow together with the feet, can add uncertainty to a step on the ground but do not significantly limit walking (see Fig. 8).

Sensing sensations: being inside/outside

However, when I formulate the phenomena graphically and represent them through a supposed material touching the skin, I am not drawing the sensation itself. Rather, it is the combination of a visually perceived body and a material that can evoke sensed phenomena. Sensing a sensation, I do not feel the body boundaries as they are shown in the drawings as contours, except the body is in touch with an external object. And I do not sense as if looking at my body from the outside. So, I attempted to draw only what I sense.

Following the conspicuous sensations with a pencil, the visual representation (see Fig. 9) shows that perception can go beyond the physical and visual boundary of the body, in a fluid transition into the surrounding space. Although I did not focus on the visual appearance of feet, they became visible in the drawing.

This led to going one step further and forgetting about the visual appearance of the body as much as possible. But how can I actively forget what is stored unconsciously? And don't the very effort of forgetting draw attention to the thing to be forgotten? For this attempt it is not very helpful, even a complication, that I have been drawing bodies, as an artist, for many years and able to do it by heart.

In addition, there is an unconscious bodily awareness, what PAUL SCHILDER calls the "body schema" (*"Körperschema"*), which concerns the spatial perception of body parts in relation to each other, formed by sensations from previous impressions (SCHILDER 1923: 2f). He shaped, among others, the concept of the "body schema," but he



Fig. 6 Barbara Graf, Drawing 189, 2017, graphite pencil on paper, 29.7 × 42 cm.

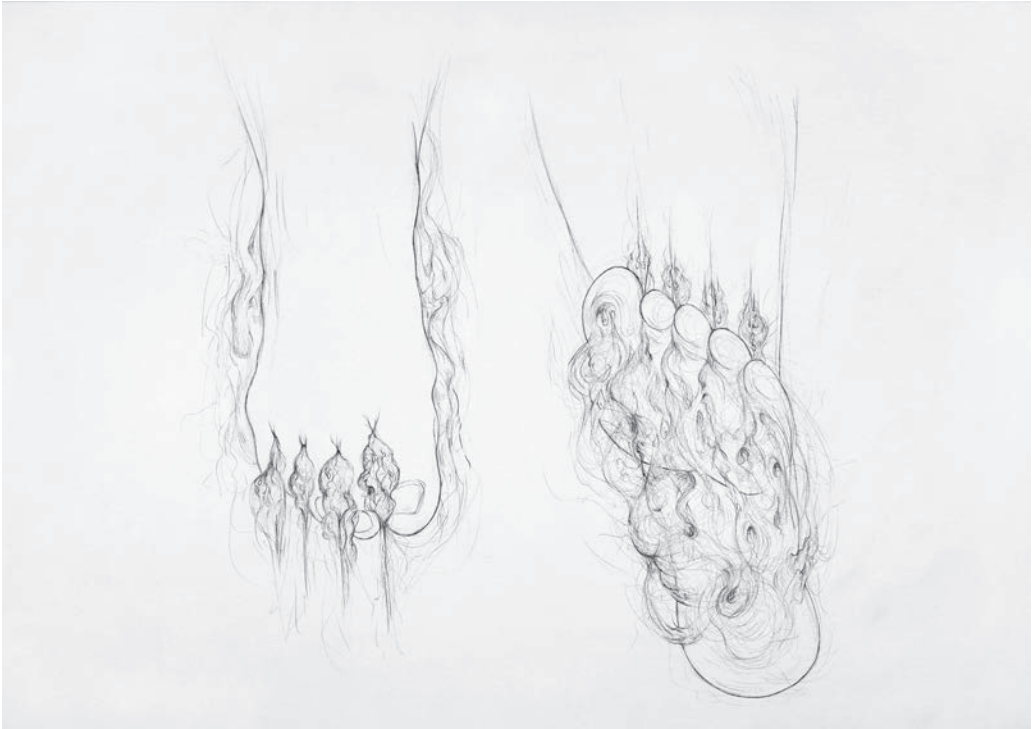


Fig. 7 Barbara Graf, Drawing 250, 2021, graphite pencil on paper, 29.7 × 42 cm.

did not clearly distinguish it from the (inner) “body image.” This different use of terminologies, or translations, contributed to an ongoing dispute. The discussion on “body schema” and “body image”—a relevant, or even main, topic of EDMUND HUSSERL (1950), MAURICE MERLEAU-PONTY (2002 [orig. 1945], 1994 [orig. 1946/47]), JEAN-PAUL SARTRE (1985 [orig. 1943], FRANÇOISE DOLTO (1987 [orig. 1984]), JUAN-DAVID NAISO (2011 [orig. 2007]), SHAUN GALLAGHER (2021), and many others—is far too complex to even consider particular aspects in detail here. Nevertheless, I would like to mention them because their concepts support some of the thoughts, questions, and contexts of this artistic research. In addition, HUSSERL, MERLEAU-PONTY, and SARTRE are the main authors referred to by the phenomenology and medical humanities experts quoted in this text.

Quasi-seismographically recording

Back to the drawing, in which I tried to ignore both the proportion of the physical body and its external appearance (see Fig.10). I only record what deviates from ordinary body sensation and draw these deviations in the size and intensity they are sensed—in LEDER’s words, everything that goes beyond the “absent body”—however, this poses insoluble problems. Already, the attempt to create a veritable mapping of these striking sensations gives attention to even previously inconspicuous parts of the body. So, I try to record the conspicuities quasi-seismographically, but the “tool” and the subject of the recording are the same. MERLEAU-PONTY points out that the very expression “with senses,” already targets the core of the problem. “The sensible is what is apprehended with the senses, but now we know that this ‘with’ is not merely instrumental, that the sensory apparatus is not a conductor” (MERLEAU-PONTY 2002 [1945]: 11).

It cannot be overlooked that the observing body is identical with the observed, but this is pre-

cisely inevitable in the case of introspection as a practice of lived sensations. This is why I call the procedure “quasi-seismographic.” The notion of the seismograph points to an external recording body and “quasi” relativizes the separation of inside and outside.

Another problem is, since a drawing is created over a certain duration, it cannot be a snapshot of sensations at the very moment, and I do not know whether fine sensations become stronger through the recording process itself or change independently in the meantime. And a crucial question is: How decide on a structure that should embody, for example, tingling, stinging, or a tension?

Intuition and unconscious language

Forgetting is nevertheless a relevant strategy, but it can only be a partial fading out of pre-knowledge, since I still need a language that enables the transition from sensation to perception to visual representation. To better describe the process of temporary forgetting, I propose a setting of two

brackets that embrace the practical drawing process. Reflection and analysis are outside of these brackets. Doing the pencil lines is characterized by an intuitive process to maintain the flow of drawing at all. Intuition is the basis for accessing past experiences and previous thoughts. They are individually and culturally shaped, and this intuitive approach allows them to appear and embody themselves in the drawings by accessing a kind of alphabet of articulations of lived experience. It is not necessary that they take the path of verbal formulation. This seems paradoxical since it is precisely a certain pre-knowledge that should be forgotten and regulation is needed to exclude at least some of it. Of course, this is a flawed construction because the intention of this setting already influences the intuitive recording and thoughts that occur during the process of drawing, which would actually be intended for outside the bracket. If I concentrate on the movement of the hand and the touch of the pencil on the paper, tracing inner-bodily sensations as if the paper were an alternative body, I can suspend at least some of the



Fig. 8 Barbara Graf, *Drawing 215*, 2019, graphite pencil on paper, 29.7 × 42 cm.



Fig. 9 Barbara Graf, *Drawing 208*, 2019, graphite pencil on paper, 29.7 × 42 cm.

pre-knowledge. When I am outside this bracket, I can think about what has unconsciously arisen and by what my repertoire of structures might be influenced, such as the studies of water, thunderstorms and deluges by LEONARDO DA VINCI.⁴

Sensory microscope: quality-intensity scale

In another approach and in order to trace the intensity of sensations I isolate them from the sensed body part. I choose a kind of visual representation like a view through a microscope. Based on the well-known pain scale, I limit the intensity levels to five and focus on the quality and how it transforms as intensity increases (see Fig. 11) (GRAF 2021: n.p.).

Pain scales are not entirely without descriptive explanations in order to function as a self-assessment tool. They are usually scaled from 1-10, or 0-10 (0 means no pain). Level 1 is usually described as “mild pain” and the last level as “worst pain possible.” Sometimes they include descriptions of how much an intensity limits everyday activity.

They are often supplemented by pictograms indicating a facial expression under a certain intensity of pain. Sometimes there are complementary graphs with the localization of a pain. If the intensity levels are color coded, in addition to numbering numbers, it is usually from green to red. If the number 0 is also part of the scale, it is marked with blue or cyan. In any case, the progression is from a cold, calm color to a warm, alarming color.⁵ Today’s numerous popular pain scales are often highly simplified compared to the historical one from 1970 and focus on intensity. This also aimed at the quantifiability of pain, but contained essential and detailed qualitative descriptions. Known as “The McGill Pain Questionnaire,” it was developed by RONALD MELZACK, from descriptions of pain experiences, to make them measurable in intensity. One of MELZACK’S scales is the affective scale consisting of levels 1–5: “nagging, nauseating, agonizing, dreadful, torturing” (MELZACK & WARREN 1970: 50 ff).

Visual representations that address the quality of pain are rare. *Dolography* is a tool to facilitate

the communication of pain, developed by communication designers SABINE AFFOLTER and KATJA RÜFENACHT (2018) in close collaboration with different pain experts and patients. It is a set of 34 cards from which patients can choose what corresponds to the quality of their pain. The visual representations are non-objective (non-figurative) and allow an associative approach. Aspects of the pain experience that are not verbalized can be addressed by acting with the cards and making it possible to differentiate qualities of pain.

Different from most of the pain scales, I have chosen five levels for my graphic representation that, however, does not correspond to the aforementioned affective scale of MELZACK. My intention is to show how the character of a sensation changes with increasing intensity. The first field shows a very subtle first appearance of a sensation that is so vague that it can be overlooked and is perceived only by giving attention. In the following fields, the peculiarity of the sensation is formed gradually. The fifth level shows a sensation in which the character of the sensation is

clearly recognizable and pronounced before it transforms, through over-intensity, into a sensation that can no longer be clearly characterized. They would be characterized by the pain being dominant over the peculiarity or by a dullness that would no longer be characterized by a specific quality.

In the first field, the pencil lines are very fine and barely visible, and develop over various levels into a clear, pronounced formation embodying, for example, a star-shaped, slightly vibrating and burning pain (see Fig. 11). In another drawing, it ranges from minimal disturbances to the perception of fibrous structures to tangle-like agglomerations (see Fig. 12).

What is omitted in these drawings is the dimension that chronic (pain-)sensations, even though they may be less intense than acute symptoms, are annoying. The drawings represent only the possible degrees of specific sensations, leaving out their duration and emotional interpretation—of course, they are not completely free from the emotional, since they are hand drawings.



Fig. 10 Barbara Graf, *Drawing 210*, 2019, graphite pencil on paper, 29.7 × 42 cm.

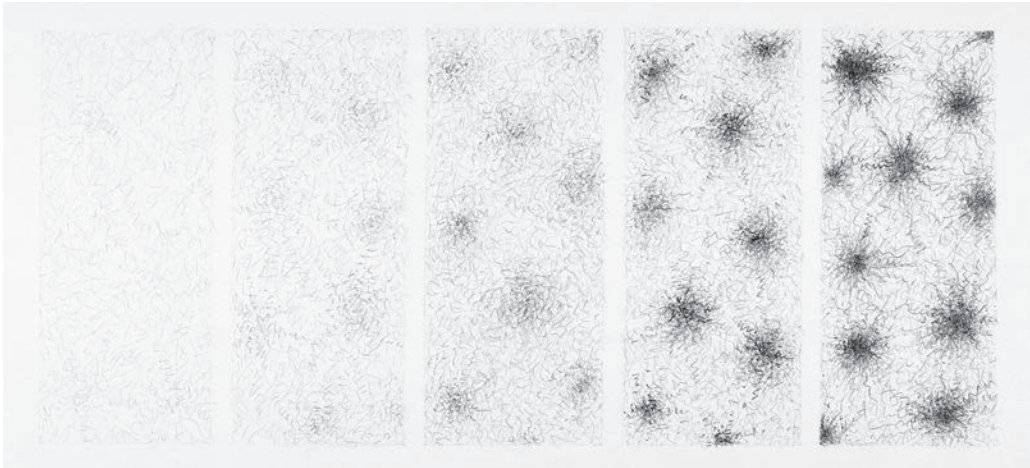


Fig. 11 Barbara Graf, *Drawing 231*, 2020, graphite pencil on paper, 13 × 28 cm.

Previous experience and expectations

In the experience of bodily symptoms, not only are immediate physical sensations decisive, but previous experiences and expectations are involved. S. KAY TOOMS examines this in detail in *The Meaning of Illness*:

“This is simply to note that the manner in which illness is apprehended and the suffering which accompanies illness, is integrally related to the whole pattern of a person’s life. [...] Cultural definitions of illness can also be a source of suffering to the sick person. Such definitions influence the behavior of others toward the person who is ill and the behavior of the sick towards themselves” (TOOMBS 1992: 43).

The knowledge of a diagnosis also influences the experience of bodily incidents. When a symptom appears or intensifies, I associate it with the diagnosed disease, even though it could also have another reason. The diagnosis can easily become part of the illness as an interpretation of lived experiences. And the anxiety of how the chronic disease could worsen, but has not yet, can disturb the relationship with one’s body integrity in the present. In *The Analysis of Sensations*, ERNST MACH emphasizes that traces of the past become effective in the perception of sensations: “Sensational stimuli can be partly or wholly replaced by memory-images. All memory-traces that remain behind in the nervous system co-operate with the sensations to set free, to assist, to inhibit and to modify the re-

flexes” (MACH 1914 [1903]: 172). Consequently, sensations are flexible in their perceptual meanings and could also be modified or overwritten. Nowadays, neuronal plasticity is used therapeutically for the modulation or transformation of psychical/physical traces, such as pain memory (SANDKÜHLER & LEE, 2013). Similarly, in *Transformative Experience*, L. A. PAUL describes the influence of past experiences on present ones and thinks them into the future. From the present, possible futures can be modeled by setting values and making various decisions (PAUL 2014: 105ff). In chronic illness, the speculation of possible subjective futures is very crucial, not because we know how it will be, but in order to have an active part in the modelling of future experiences. Even if it seems paradoxical to decide for the future, it is important for the present and future, and PAUL emphasizes the potential of the choice:

“When you consider what might happen in your future, your consideration involves an imaginative reflection on what it will be like, from your point of view, to experience the series of future events that are the mostly likely outcomes of whatever it is that you choose to do” (ibid. 106).

Legibility and reception

Since my research is not based on a quantitative study of the reception of visual representations, but I have nevertheless collected numerous re-

actions, reflections, and responses, I would like to summarize some aspects of the feedback.⁶ The drawings could also be read quite differently if there were no information that they embody physical sensations. All the people who responded know the context. The reactions are based on oral and written subjective responses. For most individuals, the drawings evoke the idea of bodily sensations and can empathize well through the visuals. In terms of empathic access with the visual embodiments, no significant differences emerged between individuals who are, or are not, affected by MS. Many of the respondents can draw on similar experiences, such as restless leg syndrome, polyneuropathy, conditions caused by accidents, other diseases, or other temporary everyday experiences. However, almost all of those affected by MS have reacted very emotionally and been relieved to see the symptoms visualized in front of them. They see it as a good way to communicate this strange phenomenon. Individuals from the clinical field see a potential to use visualizations of symptoms as an addition to verbal articulation. Some people find these evocations extremely unpleasant. And few persons, while seeing visual explorations of the body, do not relate them to their own corporeality.

Coping and healing: Instead of a conclusion

Many writers and artists—among them many women—have made records of their experience of illness and the process of dealing with it. In *The Cancer Journals*, AUDRE LORDE writes about her experience with breast cancer, surgery, pain, and loss, and about the importance of articulation: “Some of what I experienced during that time has helped elucidate for me much of what I feel concerning the transformation of silence into language and action” (LORDE 1997 [1980]: 23). As a format, the book is a combination of diary notes and reflections on them. A life-threatening disease certainly cannot be compared to a chronic disease like MS. In acute severe diseases, it is a question of surviving. In chronic progressive diseases, it is a matter of fear of relevant disabilities in the future. Nevertheless, the ways of articulating experiences and coping may be similar. For example, LORDE also writes about the essential difference between fear and anxiety:

“One is an appropriate response to a real situation which I can accept and learn to work through just as I work through semi-blindness⁷. But the other, anxiety, is an immobilizing yield to things that go bump in the night, a surrender to namelessness, formlessness, voicelessness, and silence” (ibid. 14).

In *Performative Autopathographies*, TAMAR TEMBECK describes the approaches and articulations of artists who deal artistically with their

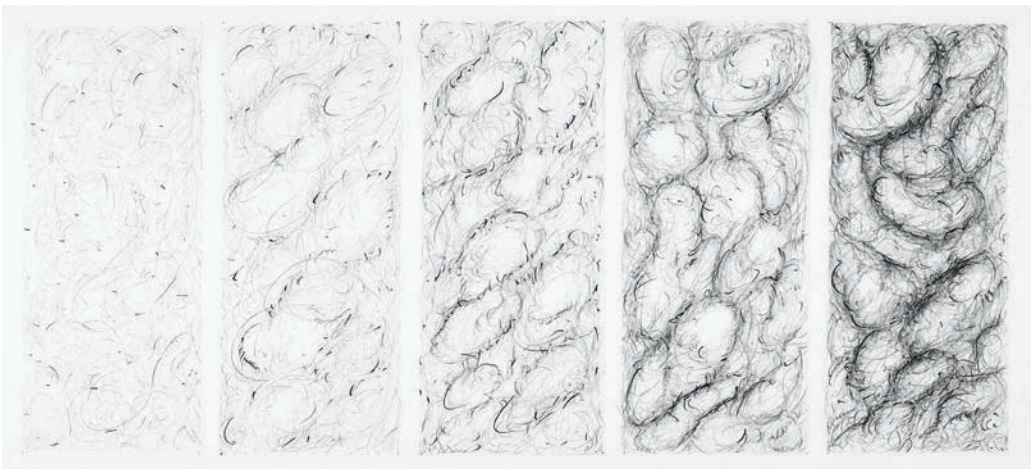


Fig. 12. Barbara Graf, *Drawing 228*, 2020, graphite pencil on paper, 13 × 28 cm.



Fig. 13. Barbara Graf, *Drawing 245*, 2021, graphite pencil on paper, 29.7 × 42 cm.

life-threatening diseases. She refers especially to the performative photographs of HANNAH WILKE or the photographic archive of JO SPENCE. In different ways, these works embody intimate self-representation through experience and suffering (TEMBECK 2009). Acute disease, hospitalization, vulnerability, loss, and the visibly altered body are the subject of artistic explorations of these two artists. In chronic diseases, there are similar strategies of transforming lived experience into aesthetic processes, but in a fundamentally different context, as it is not an exceptional situation to live with the altered body and uncertain progression.

To convey the strange sensations of chronic illness to others and myself, I search for visual formulations. Exploring subjective experiences is challenging because the “tool” of observation is the same as that of the subject of investigation. It reminds me of how NIELS BOHR describes the essential position of the tool as an integral component of observation in quantum physics (1963: 3f) as “the interaction between the objects under

investigation and our tools of observation, which in ordinary experience can be neglected or taken into account separately, forms in the domain of quantum physics, an inseparable part of the phenomena” (ibid. 18).

In artistic explorations, it is not only the tool in hand or the medium of investigation that is essential, but also and above all, the person who undertakes it, including the individual and cultural conditions. And the involvement of the observer is not a disturbance, but makes the process and actual work possible. This becomes even more explicit in phenomenological research, since lived experience is both subject and tool. Furthermore, artistic processes not only refer to reflected experience, but also have the potential to access pre-reflective, tacit self-consciousness even before conscious introspection starts (ZAHAVI 2005). The slow process of drawing allows for different accesses at the same time: a kind of self-forgetfulness in doing a pencil line, conscious and unconscious knowing taking place, remembering and reflecting on past experiences, analyzing modes

of representation, and a reflection on the matter that what is visually embodied stands in similarity but also difference to the starting point. Externalization supports coping with a chronic illness and enables to understand the alienated body as one's own again. Taking the experienced fibrous sensations into my own hand (Fig. 13), as self-empowerment, changes the perception and emotional position of what is physically experienced and does a reassessment and emotional reinterpretation of symptoms. It means a process of healing without the disappearance of the disease and enables—in spite of experienced symptoms—one to feel healthy.

Acknowledgements

The artistic research PhD project “Stitches and Sutures: Phenomenological Archive of Body Sensations” (2018–2024) at the University of Applied Arts Vienna was supported by an inspiring research environment. I would like to thank the team of Center Research Focus, the professors of the artistic research PhD program, my supervisor Barbara Putz-Plecko, my PhD candidate colleagues, and all the persons who gave me feedback and support over these years.

Notes

1 This text is an insight into my artistic research PhD “Stitches and Sutures: Phenomenological Archive of Body Sensations” (2018–2024) at the University of Applied Arts Vienna (<https://phaidra.bibliothek.uni-ak.ac.at/view/o:72623>).

2 For the fundamental problem of representation and the gap between representation with the entities to be represented, KAREN BARAD, in her critical reflection on representationalism, introduces performative approaches and proposes terminologies such as “performativity” (BARAD 2007).

3 When I speak about cultural and individual conditions, I mean the whole spectrum of socio-cultural, gender, and economic imprints. This is not only relevant for the perception of sensations, but also for the vocabulary that is available to me (belonging to Western culture) for the articulation of sensations.

4 In the Royal Collection (UK) there are a large number of drawings by LEONARDO DA VINCI Showing the movement of water, as well as studies of various weather situations. If I think of them not as an external incident, but as internal bodily phenomena—the graphic structures can well be understood as bodily sensations. They can be found under “Studies of Water,” “Deluges,” and “Tempests” and were created c. 1510–18. Royal Collection Trust,

United Kingdom. <https://www.rct.uk/> [12.06.2024].

5 There are a large number of pain scales. They contain not only the numerical scale, but are equipped with further descriptions, pictograms, or colors. This is also the base of their readability and accessibility. Depending on the age, culture, or gender of the person affected by pain, some are more suitable or accessible than others and require further explanation in use since not every person has the same verbal or visual preconditions. A few are listed here, named according to the person or place of creation: McGill Pain Questionnaire, Mankoski Pain Scale, Wong-Baker Faces Scale; or scales according to their visual form or category: VAS (Visual Analog Scale), CAS (Color Analog Scale), NRS (Numerical Rating Scale), CS (Categorical Scale), SAS (Smiley Analog Scale), FLACC (Face, Legs, Arms, Crying, Consolability).

6 The responses are woven into a polyphonic textual fabric in the chapter “Resonating Voices” of the PhD project. I had asked over forty persons to react to my artistic works. These responses include feedback in the form of resonance, evocations, reflections, expectations, associations, questions, as well as reactions indicating affective or intuitive approaches. In addition, I include feedback that came from lectures, talks, and the colloquia of the PhD in artistic research. Six feedbacks are from persons who are also affected by MS. The respondents are active in various disciplines such as the arts, art history, anthropology, medicine, medical humanities, psychiatry, philosophy, and other professions.

7 Black lesbian feminist AUDRE LORDE—as she calls herself—was half blind since childhood. After the mastectomy, she refused to wear prostheses. This is also consistent with her political position in other contexts. She was for the visibility of otherness. She died of cancer in the year 1992.

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As Far as I Can Record

Constructing the Representations of Living with Dementia in a Personal Documentary Film

ILEANA GABRIELA SZASZ

Abstract This account draws on my experience as a practitioner filmmaker documenting my father's experience of living with dementia. The scope is to analyze how the intimate relationship between me as a filmmaker and the people portrayed in the film shapes the construction of the visual representation of the experience of living with dementia. This reflection is placed in the larger frame of the cinematic and media portrayal of mental illness. Visual portrayal of circumstances that involve people struggling with mental disorders, calls for a particular awareness of the responsibility and accountability of documentary filmmakers who assume such endeavors. Personal audio-visual engagements have been viewed as a possible answer to the problem of representation raised by the ethnographic and documentary practice. They are part of a broader 'social movement that blurs the lines between public and private life' (Aufderheide 1997). Throughout the process, the filmmaker assumes interchangeable roles of both insider and outsider. The subjective position of the filmmaker subverts the aspiration to objectivity, realism, and precision of traditional documentary discourses. Drawing on my experience as a practitioner filmmaker documenting my father's experience of living with dementia, I discuss the methodological challenges that emerged during the process of film production. What are the cinematic strategies of reinterpretation, reconstruction, and understanding of self and otherness? How does such a level of access and intimacy affect the construction of the narrative of living with dementia?

Keywords: personal documentary – mental illness – media – cinema

This account draws on my experience as a practitioner filmmaker documenting my father's experience of living with dementia. It has been a decade since his diagnosis and my first recordings of him. Currently, the film is in the early stages of editing. Going through the footage over and over again has allowed me to revisit the decision-making process while filming on-site and to identify the factors that have influenced the content of the narrative and the narration choices. The scope of this paper is to analyze how the intimate relationship between me as a filmmaker and the people portrayed in the film shapes the construction of the visual representation of the experience of living with dementia. This reflection will be placed in the larger frame of the cinematic and media portrayal of mental illness.

Depictions of mental illness in documentary films call for a reflexive consideration of the

responsibility and accountability of filmmakers who assume such endeavors. Both fiction and nonfiction cinema and media have created harmful portrayals of mental illness. Personal audio-visual non-fiction films have been viewed as a possible answer to *the* problem of representation raised by the ethnographic and documentary practice decades ago. BILL NICHOLS (1991) has seen the emergence of personal documentaries as a political response and a potential solution to the debate about the power, authority, and legitimacy of creating representations of others. The proliferation of personal documentaries is part of a broader 'social movement that blurs the lines between public and private life' (AUFDERHEIDE 1997). Whether the filmmaker is in front of or behind the camera, whether one uses images from their personal archive or observes current situations from everyday life with the camera, wheth-

er one uses voice-over or different interview formats, in these documentaries the limit between public and private is constantly discussed and negotiated. The co(i)mplication, meaning 'both complex and interpenetration of 'subject/object identities' (RENOV 1999), leads to a collaborative process that speaks about the real world. The self is exposed and reflected through a 'mosaic' reconstruction of the histories and the representations of private lives of intimate others.

The subjective position of the filmmaker subverts from the beginning the aspiration to objectivity, realism, and precision of traditional documentary discourses (NICHOLS 1991). Throughout the process, the filmmaker assumes interchangeable roles of both *insider* and *outsider*. What are the cinematic strategies of reinterpretation, reconstruction, and understanding of the familiar other? How does such a level of access and intimacy affect the construction of the narrative of living with dementia?

For the past ten years, I have been engaged in making a documentary film about the effects of mixed dementia on the everyday lives of my parents. The production strategy on-site went through many changes during this time. There have been situations of shooting a certain event or moments of crisis, weeks of recording the everyday routines, planned interviews but also periods of pauses. I further want to discuss the challenges that emerged during this time. It is an analysis of the choices I made as a filmmaker while shooting on-site when the site is the lives of intimate others. How far can one go with a camera into their personal universe? What are the limits that emerge during the construction of the filmic representation? To answer these questions, I will bring forth my personal experience as a filmmaker working in the private universe of my family and embed it in the wider tableau of filmic representations of mental illness. The analysis will highlight the decision-making process of the filmmaker, the daughter, and the key moments of negotiations between the two personas.

Portrayals of mental illness in film have been a significant source for the reinforcement and even formation of stereotypes. Film is a universal language that has fueled the collective imagination with stories that reflect societal hopes and fears but also offer new meanings and under-

standings about the world around us. Cinema and media tend to emphasize violent, aggressive, bizarre behaviors that serve narrative scopes. Mental challenges often become central to character construction and development. STEVEN HYLER *et al.* (1991) identifies the following common typologies: the homicidal maniac, the rebellious free spirit, the enlightened members of society, the female seductress, the narcissist parasite, and the dehumanized zoo specimens. To this, JANE PIRKIS *et al.* (2006) add the portrayals of irrational, confused characters whose problems of delayed development are often used for comic relief and the hopeless victims incapable of adapting to social norms. Harmful representations pervade the construction of other elements in the universe where mental illness is manifested. Doctors and psychotherapists also tend to fall into archetypal categories: 'the bearded incompetent' with an accent (SCHNEIDER 1987, ORCHOWSKI *et al.* 2006, PIRKIS *et al.* 2006), the one who finds miraculous cures, 'the evil scientist' (SCHNEIDER 1987, ORCHOWSKI *et al.*, 2006, PIRKIS *et al.* 2006), the ones who cross professional boundaries to engage in personal, sometimes sexual relationships with the patient (ORCHOWSKI *et al.* 2006, PIRKIS *et al.* 2006), the rational who in the end is proven wrong by inexplicable cures (ORCHOWSKI *et al.* 2006, PIRKIS *et al.* 2006).

Considerable research has highlighted the impact cinema and media depictions have on audience perception of mental illness. Stereotypes can harvest negative attitudes toward people experiencing such disabilities and reinforce barriers and social distance (SMITH *et al.* 2019, PIRKIS *et al.* 2006). The pervasiveness of such beliefs along with misrepresentation of therapists, doctors, and course of treatment may lead to unrealistic expectations or not seeking help at all. Stigmatization discourages people from engaging in social interactions and increases alienation beyond the degree of their illness (BEACHUM 2010). The appropriation and perpetuation of traditionally harmful visual representation by the media and cinema leaves positive depictions with little effect on the negative social attitudes of the public. However, studies on public reception of documentaries depicting characters diagnosed with schizophrenia (PENN *et al.* 2003, KIMMERLE & CRESS 2013), have shown that they do have a better potential to in-

form the public on the experience and manifestations of mental illness.

Due to documentary films' relation to reality, the public expects to learn about actual people and events (ANDERSON 2003). The dichotomy 'fiction films versus documentaries' has been consistently criticized by film studies scholars (NICHOLS 1991, 2001, GODMILOW & SHAPIRO 1997). There is reality in fiction films and there is fiction in documentaries. The variations between the two stand in their relationship to the truth. Documentaries are constructed representations of 'a particular view of the world' (NICHOLS 2001). They are expected to be not only plausible, as in the case of fiction, but truthful depictions of events. The fictional aspect of reality is produced by the selection of what is captured on camera and the choices the filmmaker makes in the construction of the story. The relationship between the author of the film and the audience is set from the beginning by the convention of the way the film is presented – fiction or documentary. What is essential in our cultural context is the trust in the filmmaker's good intentions.

Content (single shots, characters, and narrative lines even) is edited out of the final version of the film due to constraining of current conventions in terms of form and distribution. The distribu-

tion possibilities of nonfictional video production films are expanding. Filtering the information to mislead the audience is considered unacceptable. However, these types of misrepresentations and omissions are sometimes made due to a lack of understanding of the matter. Attempts to portray trauma behind mental illness can contribute to 'breaking the stigma' (BUTTIGIEG 2020). However, creating a narrative through correlation to explain the cause of a mental illness or emphasizing the decline of personhood for dramatic purposes can lead to the reinforcement of stereotypes that perpetuate fearful, piteous, condescending attitudes towards the people suffering from such a disease.

Important attempts have been made to give voice to the ones who have been diagnosed with mental illnesses, but the outsider perspective of the filmmaker prevails in the way the story is presented. AAGJE SWINNEN (2012) denounces VAN ES's directorial choices in *Verdwaald in het geheugenpaleis* (eng. Lost down memory lane;2010) – which had the support of Alzheimer Nederland. The narration is constructed in such a way that enhances the constant threat of being moved to a large-scale facility. The film ends with the people discussing euthanasia. Such a perspective reduces people to their illness, disregards other aspects of their identity and reinforces a sense of distance



Fig. 1 My mother helping my father get dressed.

and otherness. A similar effect was created by the PBS program 'Out of the Shadow' (2008) which was presented as featuring 'the science and treatment of depression with intimate portrayals of families and individuals coping with its wide-ranging effects'. The ninety-minute documentary 'educates the audience about the illness' but the expository style 'creates a separation between subject and viewer' (HUETTER 2019). What cinematic form could undermine the reproduction of 'the symbolic boundaries between 'us' and 'them' (CROSS 2004)?

The construction of visual representations of mental illness raises questions about the power, responsibility, and legitimacy of the ones who engage in such endeavors. The BBC TV series 'Video Diaries' (1990-1996) erodes the boundary between public and private and explores the everyday lives of people suffering from mental illness. Visual engagements of self-representation don't look to explain, but make an 'implicit request for the viewer to recognize the reality of the speaker and to incorporate that reality into his or her view of the world' (AUFDERFEIDE 1997). The failures of conventional cinematic approaches in documentaries that portray mental illness suggest a need for an exploration of more open formats. Documentaries like 'Mum' (Netherlands, 2009) by ADELHEID

ROOSEN and 'Us Against Us' (Romania, 2021) by ANDRA TARARA focus on the present instead of nostalgic recollections of a lost identity. 'By highlighting instead of veiling its means of production, Mum stimulates viewers to imagine people with dementia as other than lost selves' (SWINNEN 2012). The 'performative documentary' (NICHOLS 2001) depicts present interactions between 'mum' and the people close to her. The relationship between Tarara and her father, who was diagnosed with schizophrenia, is portrayed using a split screen technique in which each of them is exposed to the other's camera recording of their conversations. The two films, create a setting in which the 'mum' and the 'father' have an opportunity to reaffirm their personhood through personal interactions with the people around them (HENNELLY *et al.* 2021).

Personal, autobiographical (LANE 2002), first person (LEBOW 2012) documentaries or domestic ethnographies (RENOV 1999) are defined as 'explorations or depictions of the personal lives of the filmmaker during which family members, friends, and others are recorded in sync sound or with the illusion of sync sound' (MACDONALD 2013). These films are a result of a process that starts with a level of intimacy which cannot be achieved in any other filmic engagement (KATZ & KATZ 1988).



Fig. 3 My mother is talking to the camera about my father's illness while he is listening.

The exploration of the filmmaker's biography is not usually the focus of these films but his/her life story is interconnected with those of the people around (LANE, 2002). These engagements are never solipsistic but always imply a dialogue with 'another' (LEBOW 2012). The prior relationship offers a level of access and intimacy, unachievable in any other filmic engagement (Katz & Katz 1988). But this calls for a particularly enhanced awareness of the responsibility towards the people represented. 'Cultural assumptions that family members should, and will, protect one another lead to more stringent criteria in judging the ethics of film-makers' (*ibidem*) who choose to visually document the lives of intimate others. Even more so when family members are in a vulnerable position such as suffering from a mental illness.

Personal documentaries are a form of representation of the domestic space, of social experiences, some common, others exceptional and traumatic. Having access to how experiences are lived whether its identity, gender, illness, death, etc. it makes people become more than 'social actors who perform ritual obligations with mathematical precision without emotional dimension, or distinguished personalities' (LOIZOS 1992). Because most of the time these are independent productions are not bound by an institutional agenda or profit driven constraints, these documentaries challenge the forms through which otherness is constructed. Documentaries like 'Mum' or 'Us against us' defy public perceptions of mental illness by focusing on the affirmation of the self through the continued engagement in personal and social activities. These pluralities of subjective perspectives come to challenge public discourses on these topics. There are ways in which the histories of anonymous individuals and official history merge and contest each other. Thus, agents of change within social systems can be more easily identified through the lens of individual experiences.

From filmmaking to diagnosis and back to filmmaking

In 2013 I began filming my parents' experience in the first weeks of retirement as part of a research assignment during my MA. Like many others in post-socialist Romania, after the factory where

they spent most of their lives closed down, they faced over a decade of struggling to make ends meet by slaloming between underpaid jobs on the black labor market and unemployment. What I was hoping for was to observe and record the changes that occurred in their everyday lives as a consequence of their new status. My assumption was wrong, as their routines did not alter overnight. However, I did notice something different in my father's behavior. His daily activities were the same, as he had been unemployed for two years. However, some difficulties in the way he communicated and interacted with me and my mother caught my attention.

During the shootings, I've had several failed attempts to interview my father. It was difficult for him to give me the coherent answers I was looking for. He had never been much of a storyteller. I always thought of him as an introvert with the most inspired effortless punchlines. He is ethnic Hungarian and he always had some struggles speaking Romanian, as it is his second language. He rarely engaged in long explanations or depictions because when he did, Hungarian and Romanian grammar and lexicon collided into confusing stories. It was not unusual for him would look for the right words, and find unusual substitutes or long expressions for common words in Romanian. I never learned Hungarian (being a Hungarian was not something to be proud of) so I considered any mistakes in communication to be due to his mother tongue. This, along with 'getting older' and maybe camera shyness became a viable explanation for a while. My mind changed during the editing process. Revisiting over and over the shots of my father, away from other disturbances and stimuli, I became more aware of the scale of his speaking difficulties. The long pauses, stutters, half-articulated words, and unfinished sentences made it very hard to edit and reconstruct coherent discourses. His confused or distracted facial expressions were not something I was familiar with. He may have been an introvert but he was very focused on the conversations and his interventions were always right to the point. I insisted he'd see a psychiatrist. He was soon diagnosed with mixed dementia.

A documentary approach that relies on conventional techniques has seemingly failed in capturing the voice and experience of the person in front

of the camera when that person doesn't communicate according to social standards. It took a few years until I decided to record my father's experience of living with this new illness. As a filmmaker, I felt it was an important story to which many people could relate. As a daughter, the camera became a pretext for being present. My initial intention was to follow the everyday struggles of someone who has faced this diagnosis and how this degenerative disease is affecting this person I knew all my life. It became a process of (re)discovering a familiar context and the way is being shaped by the new reality. It also meant a search for a cinematic approach to communicate a story about someone who is losing their ability to communicate.

(Re)discovering and reframing familiarity

As mixed dementia progresses social relationships are affected by the difficulty of communicating verbally. My father was always an introverted man with a social life structured by the relationships that his job ensured. The mother, on the other hand, has an extroverted personality, which tends to overwhelm those around her and also the action within the frame of the camera. Due to the degeneration of my father's physical condition, the relationship between them became that of caretaker-cared for. Until the moment of the diagnosis, this type of dynamic was somewhat established due to her more efficient adaptation to the labor market, something that greatly imbalanced the power relations within the family during the deindustrialization period. But if up to that moment, this was an effect of a combination of social causes, the labor market and the political situation, since then, dementia seems to have defined irreversibly their roles.

The dominant attitude of my mother required finding strategies to explore my father's quiet character. The times when the two are not together are very rare. Although the communication difficulties have amplified his isolation from conversations in real life, I tried to use the camera to reframe his seeming dynamic with the people around him by focusing on my father's body language. Recording close-ups of my father while my mother was talking, allowed me to observe and capture his reactions to her manifestations.

The ironic or disapproving looks, the frowning, smiling are still very present in his face. These are indications of his presence, awareness, and perceptions of the things happening around him and contribute to a depiction beyond the apparent absent person. Another strategy to create more space for him to express himself in front of the camera was by using the camera as a catalyst and inviting him to participate in conversations up to the point of interrupting my mother while she was talking.

Familiarity with the domestic space and prior knowledge about the dynamics of the two is an advantage in anticipating actions and reactions to be caught on camera. My parents have lived in the same space since I was born. I knew where they spent most of their time, where they carried out their activities, their body language, and their reactions. I knew the bed my father would sit in after eating and that he wouldn't last very long in the same position. I knew the cat would come next to him because he is warm and always sleeps in the duvet. I knew that my mother is anxious and that when she talked on the phone she walked around the house and raise her voice. I knew how the light came through the windows and what the darkest corners were. When going shopping, I knew in which order my father would enter the stores. This type of familiarity allows a certain control over the possibility of recording spontaneous moments on camera. Small moments like entering an empty room and ignoring the camera, sitting in an empty chair in the middle of the shot, reacting behind another's back or even falling asleep informs the viewer about the level of trust and intimacy that exists between the filmmaker and characters. When filming onsite people I don't have a prior relationship with, there is a period of exploration and learning about the other's routines. The process of observations becomes mutual. While I come as the observer, I am also observed by the people in front of the camera. Trust must be built. In the first stages of interaction, I constantly inform them of the process and disclose information about my intentions. Besides the story I follow, I also often give explanations about why I'm sitting in a certain place or why I'm interested in filming certain activities that may seem banal. The distance between the filmmaker and the ones in front of the camera often finds its way onto the

screen. Nevertheless, even in the most familiar space, when relations are being mediated by the camera a distance and unfamiliarity intervenes. The filmmaker swings back and forth between the role of the *outsider* and *insider*.

Stances of the camera

Distance and closeness coexisted. My insider position became subverted by the presence of the camera and by taking the role of the filmmaker. The outsider's interest also brought us closer. My father's illness was something I was only beginning to understand. After his diagnosis, I distanced myself from them for a while. I disapproved of their life choices and lack of care for themselves. I believe it was the main reason for the deterioration both of their health. The camera was a pretext to reassess my attitude. My initial shootings had a voyeuristic perspective and the camera served the outsider's curious gaze over unfamiliar behavior. I saw my father as a victim and used searched for a confirmation of that narrative through the lenses. Constantly being present not only physically but also paying attention to what was happening on the small camera screen, reconfigured my perceptions. Up to this point, during our usual encounters, I would many times get distracted or to easily

get into conflicts. Our meetings used to be chatty and noisy. Now both my father and I were quieter than our 'usual selves'. I sat staring into the camera without speaking even for hours. He would sometimes try to say something, maybe respond to my mother, or ask me a question, but many times he would give up, after not finding his words. The function of the space changed for each of us. The kitchen had only been the place to prepare food, to talk, to watch TV. They both began to adapt their movements based on where I placed my camera and moved objects to have them more within their reach. As time passed, they also adapted the room according to my father's limited movements. They bought a more comfortable chair where my father would spend most of his time. My camera also became more fixed, just across the table from him. I began to (re)discover the domestic space and those who inhabit it. This way of observing them created the context to learn about new behaviors but also some I didn't know existed.

Video recordings allow observing people beyond direct communication, through moments of silence and small gestures. Mom's outgoing behavior attracts the attention of the people she is in the room with. By pointing cameras at my father while she was talking or doing some activity, it allowed me to observe and capture his



Fig. 9. Me and my father talking for the first time about his illness.

reactions to her manifestations. His lack of engagement in conversations turned out to be an appearance I chose to believe. I discovered reactions like looking away when there is something he doesn't agree with, the frowning, the sigh, the pursing of the lips, etc. I also witnessed her critical and disapproving attitude reflected on her face. The camera created the opportunity to observe these subtle aspects of their relationship but also shielded me from conflicts. It became a barrier that blocked the instinct to intervene in discussions or state my mind about things I did not agree. Relating the position of the filmmaker defused the tensions.

The professional stance that disciplined me to focus on the process of filmmaking revealed my mother's actions as a caregiver and her coping mechanism. While at home, her time was structured by my father's routines that she had to assist and house chores. Filming her was predictable. When I decided to follow them on a trip planning a station point or angle of the camera had to be reconsidered many times. No longer having the physical constraint of domestic space, it became almost impossible to keep her within the limits of the frame. After placing my father in a chair, sometimes she would prepare to relax in the sun, but shortly after sitting down, she would give up and look for something else to do and 'disappear from the shot'. Checking the time code of the video camera, I found that I was able to capture frames of a maximum of one maybe two minutes of her engaged in the same activity.

Reconstructing the past through interviews

Interviews have been a means through which I wanted to preserve my father's memories. They were a way of reconstructing the life story we no longer had that can't be seen. To highlight the changes that occurred after the diagnosis I believed that the past should be remembered and narrated. On the one hand, it served my initial gaze that looked to focus on what is lost and present it within a nostalgic framing. On the other hand, as a daughter, I wanted to have records of his life story, of our life stories. It became a process of preserving memory while memories fade.

The interplay between insider and outsider on the one hand brought forth information the

daughter didn't know on the other, the daughter helped reconstruct lost moments of the past. The access to this intimate situation and the openness of the two subjects, characters, was a consequence of the personal relationship between me and them. The daughter is the one who knew the mechanisms by which the two would agree to be questioned and filmed in the domestic space. The questions I raised were based on my own lived experience with them. The presence of the camera was a form of legitimizing questions I presumably knew the answer to or some that had never been asked. It brought a formalized aspect to the discussion framework. As a daughter, I had access to prior information about the past and also their trust to share it. But the camera introduced an outsider, the filmmaker, as the dialogue partner. It brought out a different attitude and a new way of relating to one another. Our usual interactions unfolded according to certain patterns and the communication was infused by emotional reactions. In this new context, my professional motivations blocked my automatic responses. A silent person appeared in front of them, not responding with laughter or anger. They repositioned themselves and unfamiliar attitudes and behaviors were revealed. I presented myself as a filmmaker and they responded as pensioners, one diagnosed with mental illness, as caregivers, not as parents. My mother's attitude shifted during the shootings from jovial and humorous to confessions about the hardship of her experience as a caregiver. My father didn't evade my questions, or dismiss them, as he did in our past conversations. Although it was the first time he made an effort to recollect with detail and emotional engagement, his ability to put them into words undermined our process.

The degree of interpenetration of my life history and theirs was so high that the reconstruction of the past was a highly collaborative process. Through the 'how about the time when...' approach, lost fragments of the past were elicited and recovered by core memories in my own biography. In the interviews with both of them, the two were 'correcting' their stories and narratives about the past or adding information to each other's 'pieces of memory'. The whole process was a negotiated reconstruction and re-assembly of memories in the form of a puzzle.

Stepping in front of the camera

A turning point was the moment I decided to step in front of the camera and reveal upfront the dynamics of our relationship. As time passed and the illness progressed, I became more aware that remaining behind the camera would not be a truthful depiction of my father's experience. The most significant aspects of his life are the relationship with my mother, me, and my brother. His personhood and his personality are affirmed through his engagement with each of us. I looked for an opportunity when my mother was away. I wanted to create a context where he would have more space for him to express himself. I left the camera on a tripod and sat next to him in a two-character frame. The camera became a catalyst for our first meaningful conversation. I built the courage to ask questions that I had asked only in my mind. I was surprised by my father's willingness to talk about topics that have been taboo in our family like his awareness of this condition and his dependence on my mother.

It was the first time in my life that I had a serious talk with my father. We've had conversations before, just the two of us, but we've never approached personal topics. The filmmaker also wanted to reveal more of this silent character. I was surprised by the willingness of my father to answer questions that were taboo in family discussions. Moreover, I discovered a greater dose of coherence in expression than was in my perception at the time. In this discussion, I heard my father say that he loves my mother, but also that he is aware of his disease and that he fears that she will not love him anymore because of this disease that makes him stubborn.

In the editing process, I had a difficult time looking at myself as a character. I considered the option of discarding the video and just preserving the sound. The lack of comfort I felt was easily visible on screen. The first time I reviewed the footage, I regretted the decision to position myself in front of the camera. It was very difficult for me to look at myself and I thought that even for a stranger it would not be a comfortable experience and would distract from the content of the father's answers. It took a while to reconsider this perspective.

The initial decision was not to position myself in front of the camera because I did not want the focus to be on my relationship with them, but rather on the changes that occurred in their lives, I came to realize it was a blind spot. I was part of the story from the beginning. When remaining behind the camera the perspective of the filmmaker is seen through the cinematic language: in the framing, the camera movements, focus, sound, *mise-en-scène*, the montage, and the structure of the story. By penetrating the line that separates inside and outside the camera frame and exposing myself along with my parents provides the opportunity to witness my reactions as a daughter to what the two are saying and doing. This moment captures very well the 'daughter's' fear of having this dialogue with the father and the filmmaker's sense of risk of exposing herself in front of the camera. It also reveals both character's vulnerable positions and fear of having this dialogue.

Conclusions

When I decided to make a documentary film it was because I wanted to make sense and create a narrative of what it means to live with dementia. My knowledge about this illness and what I imagined I am going to witness and record on camera were shaped by the films and media portrayals I was exposed to until then. The initial script was the story of a vulnerable person, a victim, whose identity will fade away by the end of the film. As the shootings progressed, the story became about a search for understanding and connection. In the beginning I was motivated by the idea that the film will be a way through which my father, whose relations became mediated by my mother, will be engaged with the outside world. I came to learn that what he needed was to be seen and acknowledged by the ones in his proximity. The process of filmmaking has recorded and also reshaped our relationships. The camera captured the transformations of my father's interactions with my mother and me after his diagnosis. Nevertheless, process of making a film became a part of our life stories and altered them.

The interchangeable roles of insider and outsider allowed taking distance and understanding from different perspective but also getting closer by rediscovering each other in new ways. Dis-

curring traumatic experiences was possible due to a rupture of our conventional ways of relating. Exposing their fears and insecurities, questioning one's identity was not part of the routine of our domestic intimacy. A new kind of framework was created in which I positioned myself as an outsider, as a filmmaker. The placement of the camera between us served as a form of legitimizing the presence of 'the other'. In this new setting my parents repositioned themselves as dialogue partners with a much more sober attitude. Throughout this process the camera has become an ally that helped me as a daughter formulate and questions I haven't thought of before or haven't had the courage address. However, the access to this experience was given by the insider, the daughter. They trusted me and I knew the mechanisms to inform them of my intentions and reassure them they will be protected.

For the daughter making this film is a form of preserving my father's memory as it fades away. As a filmmaker I hoped to invite consideration of the terms on which people that experience dementia are represented on screen and given a public voice. I decided to step in front of the camera and undermine the privileged role of an observer by also becoming observed and submitting to the risks of the public's gaze. My subjective position undermines the voyeuristic pleasure of seeing from a distance the experience of the other. Hence, the self is exposed and reflected through a 'mosaic' reconstruction of the experiences and the representations of the private lives of my parents. The story will not explain the challenges of living with dementia it will depict my experience of learning about how my father experiences this illness. Will the public acknowledge my experience? Has such a form of public representation had any potential to ameliorate perceptions of people living with dementia?

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Notes

- 1 The role of visual culture has grown considerably since the emergence of the problem of representation. Over time, the discussion framework has been nuanced by the proliferation of representations of one's own culture, or of those with whom the one undertaking the endeavor "shares the same social, cultural and linguistic background" (LIAMPUTTONG 2010). With the emergence of new modes and possibilities of practice and reproduction, new questions have emerged that interrogate the problem of representation: Who should and who are those who produce them? Are they inside or outside? What are the forms through which these representations are produced (collaborative, reflexive, problematizing cultural stereotypes)? What kind of topics do they address and how are they (re)presented?
- 2 Film website: <https://www.pbs.org/wgbh/takeonestep/depression/about.html> [05.10.2024].
- 3 Other types of defining personal audio-visual cinematic engagements: essay (RASCAROLI 2009); vernacular (DOVEY 2000), family films (MORAN 2000), performative (BRUZZI 2000) – as discussed in *The Cinema of Me: The Self and Subjectivity in First Person Cinema* (ed. LEBOW 2012) and reflexive or self-reflexive (RUBY 1988, NICHOLS 1991, MACDOUGALL 1998).

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Comics in the Time of COVID-19

Examining the Role of Graphic Medicine in Promoting the Right to Health

MARTINA CONSOLONI, DELIA DA MOSTO, MARGHERITA NERI & SARA VALLERANI

Abstract In recent years Graphic Medicine has gained in importance in various fields, ranging from clinical to activist contexts. By analysing the experiences of the Käthe Collective which created the comic book *Materia Viva* in 2020, the aim of this essay is to review the elaborations that have developed in the field of Graphic Medicine and examine its role during COVID-19. *Materia Viva* is a comic that focuses on different concepts and principles of health such as: a conceptualisation of health that goes beyond the absence of disease, the social determinants of health, health inequalities, and community participation. Starting from a review of the different uses and purposes of Graphic Medicine, the essay focuses on the context in which *Materia Viva* was born, namely the lockdowns introduced in response to the COVID-19 pandemic in Italy, and on the creative process that led to the publication of the comic book. Subsequently, the main contents of the comic book are analysed, to conclude with the description of the concrete contexts of *Materia Viva*'s development and use after its publication. Our analysis highlights how, although *Materia Viva* was created to disseminate health-related content, it has also been used in other educational, clinical and activist contexts. In this perspective its physical and virtual form, as well as its purpose are shaped by the people who interact with it, resulting in an unexpected relevance compared to the original intentions.

Keywords: graphic medicine – health inequalities – health promotion – health activism – COVID-19

Introduction

This article originates from the reflections that were developed during the conference *Visual Expression of Health, Illness and Healing*, held in Vienna in June 2022. On this occasion, we had the opportunity to narrate the experience of the KÄTHE COLLECTIVE in creating a comic about health and specifically on the right to health. The comic, *Materia Viva* (in English *Living Matter*), is self-produced and Open Access, developed in 2020, during the COVID-19 pandemic in Italy. The KÄTHE COLLECTIVE consists of a group of researchers and activists with different educational backgrounds and professional profiles who decided to approach health-related issues through the construction of comics.

In this paragraph, we will illustrate the aims and the structure of the article as well as clarifying our positioning in relation to the topics that will be addressed. Firstly, we want to specify that all the authors of this text are part of the KÄTHE COLLECTIVE and participated in the ideation, cre-

ation and development of the comic as well as in its presentation and dissemination initiatives. For this reason, when referring to the KÄTHE COLLECTIVE, we will use the first-person plural throughout the article.

The first aim of the contribution is to reconstruct the stages and trace the main features of the context surrounding the creation of the comic book *Materia Viva*. The second aim is to reflect on the nature and role of this comic in the current panorama of Graphic Medicine (hereafter GM). Where does *Materia Viva* fit into the composite framework of contexts, uses, and perceptions related to GM? A first step in achieving these two aims is to contextualise the field of GM, and then go on to explore the main features of the comic's context, namely the outbreak and continuation of the pandemic in Italy. The third paragraph deals with the main methodological aspects that guided the conception and drafting of the comic book; the fourth addresses the key themes of the comic.

Finally, the conclusions explore the collocation of *Materia Viva* concerning the different contexts of use and purposes proposed in this introduction on GM.

The many dimensions and uses of graphic medicine

GM is a narrative form characterised by an interplay between words and images and the simultaneous encounter and intersection with the dimensions of health, illness and healthcare (e.g. WILLIAMS 2012). These intersections make this medium of particular interest as it contributes to the development of new knowledge, narratives and representations, that inform conceptions of health and illness. GM is also increasingly recognised, as evidenced by the various national GM associations that have arisen recently (*Graphic Medicine Italia*, *Japan Graphic Medicine Association*, *Medicina Gráfica* in Spain). In parallel with its diffusion, GM is characterised by multiple areas of creation, contexts of use, authors, and receivers/audience. The literature identifies numerous areas of creation and application of GM, among others: illness narratives and storytelling; the clinical field; the education of health professionals, and, in general, the educational and pedagogical field; theoretical and methodological aspects of social research; communication and dissemination of content; forms and tools of activism. For the purposes of the article, it is helpful to review the main features of each field.

GM is a form of expression through which patients, caregivers, and anyone involved in the experience of illness and care can express and expand their narratives. Thus, this expressive function puts the plurality of experiences surrounding care into focus and has the potential to restore different points of view and perspectives on the experience of people. An example can be the multiplicity of dimensions that permeate the doctor-patient relationship, or the relationship between a person/the doctor with family or friends, as well as the difficulty of making therapeutic choices (JIBAJA-WEISS *et al.* 2010). For patients, graphic novels can support the development of reflective processes regarding their illness experience, also by recognizing commonalities between their narratives and other people's stories. Hence,

graphic novels become a narrative tool following the principles of Narrative Medicine (CHARON 2008).

In the clinical setting, GM also serves a purpose for healthcare professionals, fostering new ways to understand patients' experiences of illness and potentially revealing patients' belief systems and conceptions of their disease. In addition, it is a valuable tool for gaining different perspectives on the health professional-patient relationship whilst deepening the patients' point of view.

In relation to the expressive sphere and clinical field, GM has potential in the education sector, particularly for social and health workers. According to GREEN (2013), comics can teach/develop critical skills: observation, empathy, communication, and clinical and diagnostic reasoning. GM can thus be considered within the framework of the medical humanities, namely the interdisciplinary field that incorporates the role of stories in clinical practice and combines different forms of knowledge (such as humanities and social sciences), various forms of expression (literary, artistic, visual, graphic, and more) in the educational paths of healthcare professionals (BLEAKLEY 2015; THACKER *et al.* 2021; FITZGERALD & CALLARD 2016). Furthermore, as MORETTI AND SCAVARDA (2021) point out, GM can strengthen various communication and relational skills in healthcare professionals. Another potential of GM, and in general of the medical humanities, consists in including among the capabilities of health professionals also the negative ones, which means remaining in a state of uncertainty and accepting the non-linearity and plurality inherent in illness and care (BOSCO & VALLERANI 2023).

Due to their methodological potential and their analytic and theoretical significance, comics also play a role in research, especially in the social sciences (WYSOCKI 2018; KUTTNER *et al.* 2020). Namely, the ability of a comic strip to stimulate reflection and analysis on how people use images, on the different views of illness and care, or the role of visual perception in learning and knowledge processes (MORETTI & SCAVARDA 2021).

A fourth area of GM is dissemination and communication; in the research context, comics can be a way of disseminating research results in a more accessible way. GM is also understood as a public (and critical) communication strategy re-

lated to health and health measures, such as the infodemic produced during COVID-19 (KING & LAZARD 2020).

In this context, graphic novels can be linked to activism and struggles for the right to health or the recognition of a particular disease or chronic condition, such as vulvodynia (COSAVALENTE 2022)

However, this classification is somewhat blurred, as a comic may perform multiple roles simultaneously, potentially differing from its original purpose. For example, a comic strip conceived as a storytelling of a singular experience may act or be used to reduce stigma towards certain conditions, or can become an educational tool or a valuable contribution for a health professional to understand how to manage a specific pathology or interact with patients. The introduction of this GM classification is particularly useful for the second intent of this article, namely to understand the place and role of *Materia Viva* in this complex panorama that is GM.

Background of the comic: Italian activism in health during pandemic

In March 2020, Italy was the most severely affected European country by COVID-19. Every night, the official news recorded the steadily increasing number of deaths. The death rate was uncontrollable and unpredictable, as was what would happen next. The medical staff (doctors, nurses, social and health workers, and many other professionals) were reduced to exhaustion, while the continuous feeling of uncertainty and unease pervaded everyone's life. Indeed, COVID-19 had laid bare the inequalities of our society, highlighting its syndemic nature (SINGER & RYLKO-BAUER 2021) and the controversies that pervade our world, such as the uneven distribution of resources, the unhealthy commercial system which was enabling the spread of the virus, the lack of preparation and resources in health systems, and the limitations of biomedicine. In the meantime, from the 11th of March onwards, the Italian government established various emergency management measures in order to counteract the spread of the virus, first and foremost the lockdown. During the lockdown, one could not go out without a "self-certification": a document stating the reasons of proven necessity that prompted a person to leave the

house, i.e. work, health issues or to buy "essential goods". Bars, restaurants, shops, gyms, cinemas, theatres, museums, and discos were closed. Whenever possible, work was performed from home. Similarly, schools and universities implemented remote teaching. Social media, television, radio and billboards had been taken over by information campaigns, enshrining the practices that had to be adopted to reduce the risk of contagion: maintain physical distance, wash your hands frequently, cough into your elbow, wear masks and gloves. The decree that had toughened the containment measures was officially accompanied by the hashtag *#iorestoacasa* (*#istayathome*), urging people to stay inside their homes as much as possible. Therefore, for a long time, digital technologies represented the only resource available to maintain contact with surroundings and people that would have otherwise been temporarily inaccessible.

In this situation, social movements, which felt the urge to highlight the syndemic, unjust and unfair nature of COVID-19, had to rethink forms of participation and imagine new practices of resistance to ensure that we did not return to normality after the emergency as this was itself the problem (BRINGEL & PLEYERS 2020; Della Porta 2020). Public marches, demonstrations and other forms of activism were banned. As a result, political assemblies moved into the digital environment, and some activist practices were reconfigured within domestic and virtual spaces (COEN *et al.* 2022).

Even before COVID-19, there has been a long tradition of social movements in the Italian context, many of which have been active in the field of health. Indeed, during the 1970s, these forms of activism played a crucial role in the establishment of the Italian National Health Service (hereafter NHS) (GIORGI & PAVAN 2019) and in the development of essential health reforms, such as Law 180 (known as the "Basaglia Law"), which, apart from generating a new epistemology on mental health, led to the closing of asylums and the creation of a network of public and locally organised mental health services (BASAGLIA, SCHEPER-HUGHES & LOVELL 1987).

However, despite its history and the ongoing presence of numerous social movements, participative and activist initiatives on health issues currently experience different deficiencies (NEGROG-

NO 2023). Firstly, the health sphere suffers from a “democratic gap” that stems from the distance health institutions have vis-à-vis the population. This gap results from the process, begun in recent decades, of commodification and corporatisation of the Italian NHS, which has also led to a lack of involvement of the population in healthcare decision-making. Indeed, “the existing relationship between the population and the decision-making process in healthcare (but not only) is basically absent” (STEFANINI & BODINI 2014: 312). Secondly, the problem concerns the ability of social movements to be able to disseminate their contents in ways that permit the involvement of the larger audience.

Among the various experiences of activism in the field of health, there is the Dico32 campaign – an Italian nationwide movement that was founded in 2017 in order to claim the right to health and contrast the privatisation of healthcare services – from which the comic *Materia Viva* and the KÄTHE COLLECTIVE originated. Although already in the pre-COVID-19 era the Dico32 campaign had contributed to the generation of synergies between different social movements in Italy, since the beginning of the COVID-19 emergency, it was populated by numerous activists with different professional and political backgrounds, which met on a regular basis. During these meetings the group discussed various topics such as the problematic situation that was arising due to the impoverished and overloaded NHS, and the different experiences people were having in different regions. Like other initiatives this organisation faces challenges in disseminating its principles and involving new people. The comic *Materia Viva* was created with the intention of overcoming these difficulties within the Dico32 campaign.

The creative process of *Materia Viva*

In April 2020, two of us (a physician and an anthropologist), who were participating in the online assemblies of the Dico32 campaign, decided to experiment with different and new languages that could make certain concepts which were regularly discussed during the Dico32 campaign meetings (i.e. health inequities, social determinants of health, the right to health), more accessible and popular in the broader arena.

Years of training, education, and political mobilisation had made these concepts familiar and almost self-evident to us, leading us to create a comic book that could breathe new life into these principles. Indeed, as we started to question ourselves on how to construct a health comic we had the impression we were dealing with a myriad of concepts which were very familiar and inspiring but often difficult to disseminate. Many of these were extremely technical, scientific-academic debates, while others had been developed in the 1970s, when social movements had contributed to the foundation of the Italian NHS (GIORGI & PAVAN 2019). However, due to the current situation of the healthcare system (characterised by a strong commercialisation of health) and of the field of health activism (NEGROGNO 2023) these concepts felt extremely distant. Indeed, as FRANCA ONGARO – an Italian activist who was one of the main protagonists of the Italian psychiatric reform who introduced the importance of class and gender analysis in mental health – states, we found ourselves dealing:

With a dead thing: words, judgements, speeches, reflections that did not directly give an account of the facts, of the minute things that were changing step by step and of the meaning they were taking on. It was a ‘reasoning about’ an experience – critical and self-critical – whose vitality, physicality, fatigue, concrete contradictions, anxiety, difficulties, affectivity, sense of relationships and ties, however, escaped (ONGARO 2018: 8).

However, as those concepts and political positions made us feel alive, and made us recall all the moments in which we had incorporated them while studying or debating, we decided to give those concepts a second and new life. By wiping the dust off those distant and technical concepts, we re-narrated them through drawings, giving them new meaning and bringing *Materia Viva* to life (*Living Matter* in Italian).

As the COVID-19 pandemic continued to devastate lives and the ensuing lockdown measures confined us to our homes, we began to share this idea with friends and comrades. Within a couple of months, the group started to grow and trapped within it doctors, anthropologists and a sociologist. At this point, we started wondering about what name to give to this new artistic collective.

After a few weeks of research, we came across the works of KÄTHE SCHMIDT KOLLWITZ (1867–1945), a German artist who dedicated her art to depict the effects of poverty, hunger and war on the working class (KÄTHE KOLLWITZ MUSEUM 2023). KOLLWITZ had a strong political background, committed to socialism and pacifism, which entrenched her artwork through the light of social justice (ASHTON 2016). However, in 1933, after the establishment of the National Socialist regime, the Nazi party forced her to step down from her position on the faculty of the *Akademie der Künste* (where she was the first female professor), and her works were removed from museums. Her story and political background inspired us to name our collective *Käthe*.

Regarding the comic style, we took inspiration from LIV STRÖMQUIST, a Swedish comic artist engaged in the illustration of sociopolitical issues from a feminist perspective. We thought her work was particularly interesting as her comics include references to academic sources that guarantee legitimacy to the illustrations whilst transmitting deep and complex themes such as power inequalities and injustices (e.g. STRÖMQUIST 2018).

However, in addition to including excerpts from scientific literature and portraits of their authors, many of our frames also incorporate anatomical and botanical illustrations with expired copyright. This process gave us the impression of giving those old images a new life; furthermore, by taking them out of context, we were re-signifying them, replacing their positivistic biomedical paradigms with concepts that we felt were more aligned with our perspective.

Working together

Considering the emergency measures that had been introduced (i.e. the lockdown and travel restrictions) and the fact that we all lived in different Italian cities (Bologna, Naples, Turin), we were forced to work online. Throughout 2020, we used a Telegram group to give each other various updates and a presentation on Google Drive to share ideas and build the comic together. In our experience, the digital environment (PINK *et al.* 2015) and technological tools have played a generative role. We did not look at our laptops with mistrust, as it was through them that we had a way of con-

necting with something outside our homes. While in our domestic lives we were busy carrying out our work and sharing our “new strange day-to-day lockdown lives” with our housemates, through our computers we could open up an unusual space for our creativity.

We first had a few brief discussions on what topics we wanted to address and in what order, we then all started uploading sketches of drawings and drafts of texts onto the shared presentation which was shared and editable by all members of the COLLECTIVE. As none of us had any expertise in communication or drawing, at the beginning we were very sceptical about what outcome to expect, for this reason we did not even consider buying a proper graphic tablet until April 2021. Up until that moment, we had drawn using a simple tablet and our fingers, and those of us who did not have a digital device to draw with, drew on paper, and the others would patiently redraw digitally.

Intersecting different epistemologies and desires

Since we come from different disciplinary fields, the construction of the comic book was also an opportunity to combine different perspectives and knowledge and develop mutual empowerment practices. Indeed, while two of us had gone to medical school, the others were Ph.D. students in Medical Anthropology and Sociology. However, as we started to work together, we soon realised that although we had heterogeneous educational backgrounds we were united by similar political perspectives and activities. Indeed, despite the different theories we had been exposed to, we all believed health was a strongly political concept and issue, and this made us participate in different activist groups as well as setting the basis for our work together.

One of the first things we established within our group was to adopt a transfeminist positioning. Guided by transfeminist practices, we established a focus on mutual care practices within the group. The idea was that what the COLLECTIVE produced would respond to our desires and needs, and that it would not become yet another work commitment with defined deadlines and roles. We wanted to build a comic together as a form of “pleasure activism” (BROWN: 2019), giv-

ing space to what made us feel good and what intrigued us. As BROWN defines it:

Activism consists of efforts to promote, impede, or direct social, political, economic, or environmental reform or stasis with the desire to make improvements in society. Pleasure activism is the work we do to reclaim our whole, happy, and satisfiable selves from the impacts, delusions, and limitations of oppression and/or supremacy. Pleasure activism asserts that we all need and deserve pleasure and that our social structures must reflect this [...] Pleasure activists believe that by tapping into the potential goodness in each of us we can generate justice and liberation, growing a healing abundance where we have been socialised to believe only scarcity exists [...] Ultimately, pleasure activism is us learning to make justice and liberation the most pleasurable experiences we can have on this planet. (BROWN 2019: 11)

Out of this approach, we slowly realised that *Materia Viva*, and more broadly the KÄTHE COLLECTIVE, acted as the container or refuge for the desires of each one of us. In some moments it meant a way to “switch off” after an exhausting workday, in others a way to connect with someone or something else which was outside the domestic context. Similarly, if for some of us it the Collective represented the only feasible possibility of commitment to a political project in those particular pandemic moments, for others it also had a therapeutic role.

Living matter: Contents of the comic

In the next three sections we will describe the main themes of the comic, highlighting the reasons we decided to address such topics and the theoretical frameworks we referred to in *Materia Viva*. The first section analyses the development of the concept of health, the second focuses on the factors which influence people’s health, while the third one emphasises the role of communities in contrasting inequalities.

What is health

The comic book starts with a crucial question: what is health? Several contributions have tried to offer a definition of this concept (GADAMER 1996; HEM 2010; MACHTELD *et al.* 2011; GODLEE 2011).

As we write in the comic, at first glance and from a naive perspective, it may seem simple to answer this question: “Health is when we are well, when we are not sick!” (KÄTHE COLLECTIVE 2021)



Fig. 1

From an anthropological perspective, we can observe that concepts such as health, wellness, disease, sickness are shifting and unstable, because they not only depend on one’s conception of the organism, but also on its relationship with the environment. Therefore, these definitions are necessarily affected by the social, cultural, and historical context in which they are formulated, as well as by the person who formulates them (QUARANTA 2014).

We recover FOUCAULT’s work to show that the logic of “health” as the “absence of disease” lies its roots in the birth of clinical medicine in the 13th century (FOUCAULT 2012 [1963]). In the teaching hospital, the knowledge of the human body was built up through inspection, examination, and analysis of corpses. In this context, precise relationships were established between those who possessed knowledge and could act and those who were passive and inert: the medical-scientific gaze from above turned to the corpse and limited itself to observing the body, as if it were just dead matter, without any interaction with the world it lives in. Yet our health is not unrelated to what happens around us, nor do the diseases we have always prevent us from living fully.

As the years have gone by, also in the field of public health, the concept of health has moved from a “negative” definition – where health was understood as the absence of disease – to a “positive” one, affirming health as a value in itself and not as opposed to the absence of something else. For example, at the time of its establishment in 1948, the WORLD HEALTH ORGANISATION (WHO) explained that health is not simply the absence of disease or infirmity, defining it rather as a “state of physical, mental and social well-being”.

In respect of this definition of health, ONGARO, wrote:

From definitions of health as the “absence of disease”, which perpetuate a clear, unrealistic separation between one and the other, we move on to “a state of physical, mental and social well-being”, which involves the whole of a person’s life, suggesting that health is something that has very little to do with medicine and its intervention (2012: 27).

According to ONGARO, illness is conceived as a loss of something because nowadays life continues to be represented only by absolute health, in other words only a completely efficient and productive person can be truly considered healthy. This is also determined by the fact that biomedicine continues to have “a knowledge monopoly” on the definition of what is health and what is disease, stripping away the experience of our subjectivities. In ONGARO’s words: “It leaves us at the mercy of an unknown body and a life that is never ours” (*ibid.*).

In ONGARO’s approach, health cannot represent “the norm”, it cannot be a project that has value in itself, but acquires its meaning in living life, of which illness and death are inevitably part. In this perspective, FRANCO BASAGLIA, an Italian psychiatrist and activist who also was one of the main leaders of the movement for the closure of asylums, argued that biomedicine has to recognize that the body is not only an organic object but is also social as it represents the “product of struggles” (BASAGLIA, ONGARO & GIANNICCHEDDA 2000). He referred to this as the “political body”, as it is shaped by power relations that lay within and control society (PIZZA 2007). This is done through the development of social norms on the basis of different scientific disciplines, such as

biomedicine, that by defining what is normal and what is not it manipulates people and consequently their body. In the comic we tried to synthesise these concepts and make them our own, and we write: “Health, just like illness, is not something that happens only in a biological body, but in life.” (KÄTHE COLLECTIVE 2021).

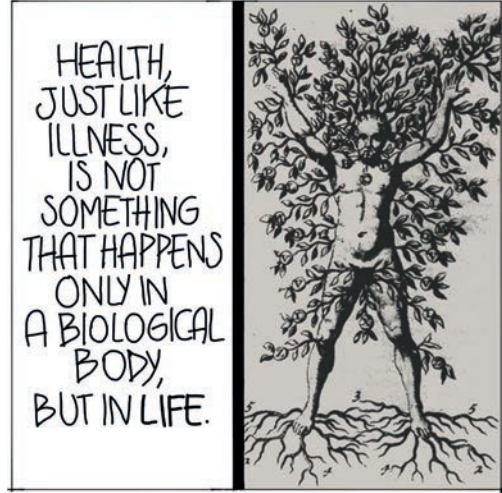


Fig. 2

Health inequalities and the right to health

The perspective designated in the previous paragraph places health within the social, economic and political context in which people live. Therefore, the factors influencing health are various and multidimensional: the social and physical environment, relationships, income, working and housing conditions, etc. These factors are defined as “social determinants of health” and together they participate in the health status of people. However, the different factors are unfairly unequally distributed within societies, and this is why we refer to them as health inequalities rather than health differences (CARDANO 2013). This inequality in the distribution of protective and health-promoting factors produces the so-called “pathologies of power” (FARMER 2004), which materialise in people’s lives in very different ways: e.g. neonatal mortality, infectious diseases, gender-based violence, political violence. The conditions of inequality mean that the “health” of some people is made possible by the “sickness” and suffering of others.

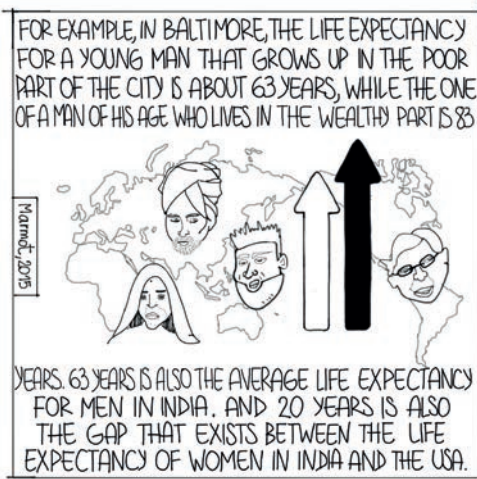


Fig. 3

Therefore, health inequalities can be defined as avoidable and unfair differences in people’s health status caused by an unequal distribution of resources intended in their multidimensionality. Indeed, inequalities do not occur “by chance” and do not depend on biological factors. On the contrary they are a) systematic, i.e. they are distributed consistently and non-causally within the population; b) socially determined, i.e. they derive from social processes and not from immutable natural laws and are not subject to individual control; c) pervasive, i.e. they always work to the dis-



Fig. 4

advantage of the most marginalised (STEFANINI, ALBONICO & MACIOCCO 2006). In other words, it means that a person’s socio-economic position influences the risk of mortality and morbidity, and this risk grows in inverse proportion to the socio-economic resources of individuals. For example, the British epidemiologist MICHAEL MARMOT speaks of a “status syndrome” to define a health risk condition caused by poor control over one’s work, loss of autonomy and low social participation, and believes that these factors are associated with an increased cardiovascular risk (MARMOT 2005). Thus, health inequalities limit the possibility of living a longer and healthier

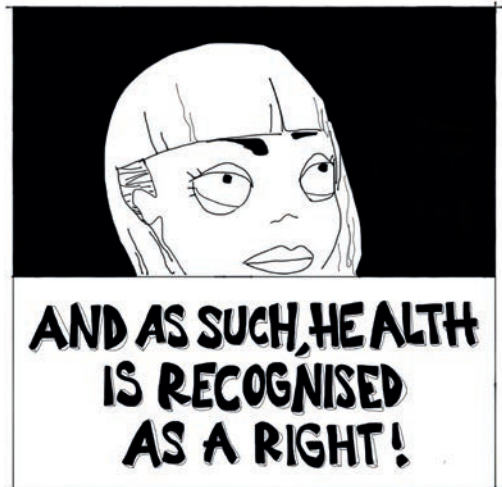


Fig. 5

life because they reflect an unequal distribution of protective and health-promoting factors (which in turn can be traced back to our economic and social structure), they are profoundly unfair differences. This perspective, on the one hand, makes it possible to look at the processes of health and illness as an expression and result of interactions occurring at the political, economic and social level, on the other hand, it allows an important consideration: if health inequalities are socially produced, they are avoidable and can be socially addressed. This consideration connects reflections on inequalities with the theme of the right to health, understanding health not as individual

fact but rather as a collective one. In this sense, health is capable of questioning the community in its entirety, and in this sense it is also a question of citizenship and consequently of social justice. The right to health means the right to public and quality care, without violence or discrimination, but it also means free access to drinking water, adequate housing, healthy food, good education and safe living conditions (WHO 1978). In brief, the right to health concerns a set of circumstances that allow people to exercise their right to develop and realise their aspirations, their capabilities and to live a fulfilling life (WHO 1986).

Participation and community of care

By recalling the old slogan: “Nothing about us without us”, it is possible to understand how the right to health also consists in the right to participate in the contexts in which the decisions affecting our lives are made. However, participation must be effective, and not merely representative (ARNSTEIN 1969; CORNWALL 2008; POPAY *et al.* 2021). If we observe and analyse the societies in which we live, it emerges how the right to health is far from being guaranteed to all: that is why it is still essential to recognize and defend it by participating. In this regard, a part of the comic focuses on the genesis and development of the Italian NHS. In Italy, in 1948 health became a fundamental, inviolable and absolute right and a good of collective importance (Article 32 of the Constitution). In continuity with this article, our NHS was established in 1978, with the declared aim of providing for the promotion, maintenance, and recovery of the health of the entire population. The NHS was born after years of struggle and civil and cultural mobilisation, guided by the principles of equality and equity: today, due to the progressive expansion of privatisation and commodification of services, these principles are losing substance. Alongside this process of disarticulation of the public healthcare services, there are several struggles arising in defence of the public and universal health service (GALANTI 2022). And in these struggles, the discourse on inequalities – and how to address and overcome them –, and on community participation are crucial. This was the context in which *Materia Viva* was conceived,

specifically during the COVID-19 pandemic. As it has been widely observed, COVID-19 can be more properly defined as a syndemic (SINGER & CLAIR 2003; SINGER 2009). The concept of “syndemics” points out how this pandemic crisis stems from the interaction of issues of a different nature (social, economic, health, climate) and that the biological component of the infectious agent is only one of the multiple dimensions determining the emergency. Firstly, the spread of COVID-19 interacts with social determinants of health and existing inequalities, exacerbating them and exposing the most vulnerable people to the greatest risks (HORTON 2020; BAMBRA *et al.* 2020). Secondly, the measures which were introduced to counteract the pandemic measures have an impact on social determinants, including the overburdening of health services (WHO 2021), or the prompt interruption of essential services which are fundamental for marginalised communities (DA MOSTO *et al.* 2021).

As frequently reported, the Italian healthcare system was unprepared to face and manage the COVID-19 pandemic (WHO 2020): the response was largely biomedical and mainly dealt with at the hospital level, while the NHS community-based local articulations, such as primary care health facilities and professionals, were rather inaccessible to the public, as either closed down or overwhelmed (GEDDES DA FILICAIA 2020). Although it was mainly through lockdown, i.e. people’s social behaviour, that the virus spread began to be contained, lockdown was a top-down measure that did not take into consideration the social conditions of its lived experience (CONSOLONI & QUARANTA 2021). Similarly, by dividing biomedical actions from social support, the pandemic made clear the incredible violence of the neoliberal market, the way it has robbed us of the ability to provide and receive care (THE CARE COLLECTIVE 2020). However, faced with a crisis for which no one had any valid and complete answers in advance, various formal and informal groups, including social movements, organised several mutual aid campaigns (CONSOLONI & QUARANTA 2021). As a result, some communities of care sprung up and the right to health was recognized not just as an individual good, but as a collective asset, which was guaranteed through multiple ac-

tivities, such as the redistribution of primary necessities.

In this way, the pandemic showed how it is impossible for people to function as atomised beings and that our interdependence is not only a fundamental characteristic of our communities, but it also a value on which to build new practices of care and democracy. Indeed, in the context of an unpredictable and catastrophic future characterised by climate change and the unequal distribution of resources, a community of care can transform these moments of crisis into opportunities for collective learning by developing new strategies of resistance and care.

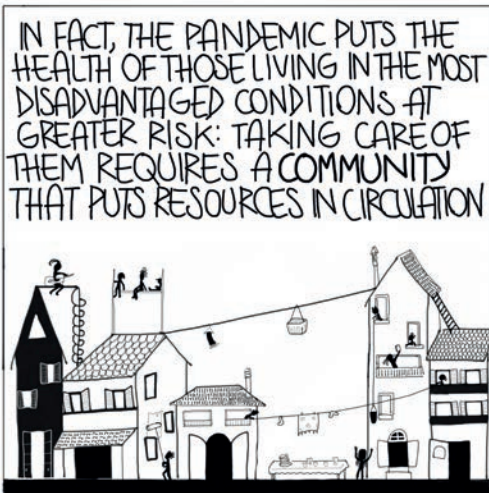


Fig. 6

Conclusions

Since 1950, each 7th of April, the World Health Assembly has celebrated the anniversary of the founding of WHO in 1948 in order to raise awareness about global health. However, in recent years other international health movements, such as the *People's Health Movement (PHM) Europe* and the *European Network against commercialisation and privatisation of health and social protection (European Health Network)*, have taken that commemoration a step further, using the 7th of April “to bring awareness to the privatisation and commercialisation of the healthcare sector” (PHM 2021). For these reasons we decided to publish *Materia Viva* (on a website, on facebook and on instagram) on

the 7th of April 2021, on the occasion of “World Health Day 2021 - Building a fairer, healthier world” (WHO 2021). It was disseminated under a Creative Commons licence, in order to allow anyone to distribute, remix, adapt, and build upon the material, in any medium or format, as long as they did not do it for commercial purposes.

Over the course of the first year, the comic started to circulate within different Italian social movements, which led to the addition of 3 pages to the original comic. Indeed, the first *Materia Viva* was not the final project but kept on changing its form taking inspiration from other experiences and contexts itself or members of the KÄTHE COLLECTIVE were involved in. The same day, one year after, thanks to the financial support of the PHM, the KÄTHE COLLECTIVE decided to print and give an additional form to *Materia Viva*. As the lockdown measures had been lifted, it was possible to meet in person and finally distribute *Materia Viva* also outside the virtual sphere. “Flesh-and-blood” *Materia Viva* was presented at the venue of a local market together with other social movements. The presentation was an opportunity to debate on different perspectives and experiences on the right to health. During the last year, *Materia Viva* became multilingual and went global: in 2022 it was translated into English and then other people all over the world offered to translate it into Spanish, French and German. It travelled all around the world lending itself to any type of use among which university lectures on the social determinants of health for medical students in Malaysia and Australia. Furthermore, through the collaboration with another collective in Bologna, *Materia Viva* also turned into an audiobook.

By analysing synchronically and diachronically on the history of *Materia Viva* it is possible to recognise some similarities and differences which recall the classification of GM proposed in the first paragraph. Although the aim of the KÄTHE COLLECTIVE was to create a comic that could facilitate the dissemination of health-related concepts, *Materia Viva* has since been used in educational, activist, and clinical contexts.

Specifically, in its first phases *Materia Viva* had been conceived as an instrument for health activism. However, unlike in other cases (e.g. COSAVALENTE 2022), it was not intended to in-

crease awareness of a specific disease, but rather it aimed to shift the conception of health as a state of possibilities, which is not necessarily influenced by the presence or absence of illness. In this sense, the objective of the comic was to widen the concept of health, conceiving it as a right which is socially and culturally produced in a specific context. In this perspective, we believe that the specific and particular conditions in which *Materia Viva* was developed have had a crucial role in shaping its primary objective, as it was the unequal impacts of the COVID-19 pandemic that made us feel the urge to do something.

However, in the process of its creation it assumed different meanings for each one of us at different moments. As seen previously, *Materia Viva* initially represented a way of exploring themes through a different perspective, one which incorporated our personal experiences and those of people with whom we share values. However, as time went by, it sometimes represented the narration of the suffering we were experiencing in that particularly catastrophic moment, gaining the characteristics of Narrative Medicine (CHARON 2008). In other cases it was a way to escape from the toxic overworking dynamics we characterise our lives as doctors and as researchers in academia, or it was also an act of resistance and of care itself, as we collectively decided to dedicate some time to it also to take care of each other.

Finally, when it started to circulate, *Materia Viva* became many other things, highlighting how the boundaries of the different fields of use of GM are in reality very blurred and intertwined. As many people have pointed out, *Materia Viva* cannot be classified; it is neither a comic nor a manual. Similarly, as seen in the previous paragraphs it does not have a unique purpose. Its physical and virtual form, as well as its intent, are shaped by the people who interact with it, performing unexpected roles compared to the reasons for which it was created.

Notes

1 *Materia Viva* is now available at the website <https://collettivakathe.wixsite.com/kaethe> [03.06.2024].

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Picture This – Medical Comics as an Impetus

Report from the Project “Art – Action – Attitude” at the Medical University Vienna, Austria

ANDREA PRASCHINGER, RUTH KUTALEK, RUTH KOBLIZEK & EVA K. MASEL

Be aware!

Providing medical care on a daily basis is a challenging task for all healthcare professionals. In multidisciplinary teams, patients - some of whom are critically ill - are treated in difficult circumstances. Not only do these teams have to keep patients and their families informed about the progress of their cases, but they also need to remain resilient. This means that maintaining high standards is crucial. In such situations, there is a need to discuss topics that are difficult to articulate. In other words, it is important to address the unspeakable or unspoken (MASEL *et al.* 2020a), which may involve situations of excessive demands, disgust, helplessness, or death. Such circumstances often require a conversation to be initiated and space to be created for discussing challenging topics (CZERWIEC *et al.* 2017).

Be flexible!

Graphic medicine, which can be found at www.graphicmedicine.org, is a powerful form of communication that utilizes visual imagery to convey ideas and raise awareness about important issues. While it may seem like a simple approach that only requires paper and pencil, it has the ability to convey complex information in a way that is often more easily understood than traditional text-based explanations. By tapping into the power of pictures, graphic medicine is able to address topics that may be difficult to express through words alone, making it an effective tool for healthcare professionals and patients alike (as shown in Figure 1). In fact, the use of Medical Comics (MC) and drawings has a long-standing history in the medical field, with numerous benefits including increased accessibility for those with poor reading or language skills. The popularity and use of



Fig. 1 Example of a medical comic; copyright of Barbara Pirker.

graphic medicine continues to grow, with a wealth of scientific research supporting its effectiveness over the past two decades (CALLENDER *et al.* 2020).

Let art be the answer!

Clinicians must see and hear each patient in the fullness of his or her humanity in order to minimize fear, to locate hope (however limited), to explain symptoms and diagnoses in language that makes sense to the particular patient, to witness courage and endurance, and to accompany suffering. (HEATH 2016:1)

Medicine is challenging - for everyone! Medical Humanities help us to classify the challenges of everyday life, to find answers and to work out solutions - this already in the training phase. The goal is to create so-called "Rounded Doctors" (WEATHERALL 1994). But also medical staff, as well as patients and their relatives, benefit from this.

Effective communication in medicine requires the ability to convey knowledge and experiences in a clear, flexible, and empathetic manner. In this context, the use of MC can be particularly valuable in presenting diverse perspectives on challenging situations and promoting the development of problem-solving skills. By using visual storytelling, graphic medicine can capture the attention of viewers and provide a platform for reflection. This approach is especially helpful when dealing with difficult, challenging, or stressful conditions, as it allows individuals to engage at their own pace, use their imagination, and learn from others. Through the use of MC, viewers are provided with a visual representation of medical situations, including the unpleasant aspects of everyday medical life, such as coping with hopeless situations and delivering unfavorable news. This "behind the scenes" view of medical practice allows individuals to connect with the emotions of the story and encourages them to take a step back and focus on the situation at hand. Ultimately, graphic medicine provides a space for the unspeakable and unspoken to be expressed, offering individuals an opportunity to share their experiences and connect with others in a unique and meaningful way.

By utilizing MC and medical picture stories, medical professionals can improve their communication skills and foster a greater sense of empathy and understanding within their practice. The visual language helps to depict serious topics and require contemplation similar to a diagnostic process, allowing viewers to perceive information, address gaps, and interpret conclusions.

But who?

The Teaching Center of the MedUni Vienna, in collaboration with the Division of Palliative Medicine, organized an MC exhibition titled "Impression - Expression - Interaction/Perception in Medicine" at the international conference Medical Humanities - Interactions between Medi-

cine and the Arts in October 2019, organized by the working group *History of Medicine and Medical Humanities* of the Austrian Academy of Sciences. The success of the exhibition led to the development of a three-year project called "Art - Action - Attitude", which was jointly managed by the Teaching Center, the Division of Palliative Medicine, and the Department of Social and Preventive Medicine at MedUni Vienna. The first exhibition of this series was supported by the Austrian Society for Comics Research and Education, and approximately 15 professionals with varying job responsibilities participated in various aspects of the project, including research, design, and web presence. Notably, both national and international artists, as well as publishers, generously donated their works to support the initiative. The project aimed to reach a broad audience, including patients, their families and friends, healthcare professionals from diverse disciplines (such as doctors, qualified nursing staff, students, trainees), and anyone interested in graphic medicine. A key focus of the project was to promote interculturality and diversity.

But what?

The Art - Action - Attitude project aimed to address daily challenges in healthcare, including stressful or complex situations that involve critical communication, using established medical comics as an accessible approach. The goal was to create public exhibitions that were accessible to all and offered free admission for visitors. The project was financed by MedUni Vienna, which covered expenses related to the design and printing costs. The exhibitions, which were held annually for three academic years (2020/21-2022/23), each focused on a specific theme relevant to the challenges faced in everyday medical practice. The themes included "Body" (2020/21), "Borders" (2021/22), and "Pain" (2022/23). The exhibition space at the Vienna General Hospital and the site of the MedUni Vienna was comprised of a corridor featuring 32 exhibition panels, with each panel showcasing a single MC artwork. For sequences of images, one theme may have spanned across two panels. Visitors could also actively participate in the exhibition through a hands-on area with various stations aimed at encouraging creativity, like

contributing words on the wall, drawing their impressions or making votings – animated by smaller panels with themes like “How do you feel after nightshift/s?”, “What makes you addicted?”.

But where?

The exhibitions were showcased in a central but peaceful corridor of the auditorium center at the Vienna General Hospital, and an area for interactive stations was provided. Despite the restrictions during the COVID-19 pandemic, measures were taken to enable visitors from outside to access this area. The open and free access should allow a low-threshold, gradual, multiple visit. This was accompanied by the disadvantage that no valid data on visitor numbers could be generated.

But how?

The project team was organized through an online platform that utilized a tool for recording and assessing exhibition proposals. Despite the various styles, approaches, and perspectives of the submissions, the best entries were chosen. The selected creators and publishers were then contacted to obtain the necessary usage rights. In addition, text blocks were positioned around the central artwork on the panels. These blocks included information such as the title, subtitle, background

details, reflective tasks, author and/or publisher information, and artwork citation.

Art – action – attitude/ body – borders – pain

Exhibition art – action – attitude/body

The project commenced with the Body exhibition, which ran from November 2020 to June 2021. The exhibition centered around the human body, exploring its complexities such as language, sensuality, health, disease, diversity, and mortality. The exhibition featured works from 21 national and international artists, in both German and English. Additionally, a brochure in German and English was created to accompany the exhibition, and a participatory area featured a side wall titled “Art – Body – Art” with works from 11 international artists.

As a special project, a 12-page comic booklet was published in German and English in collaboration with the Austrian artist Renate Mowlam, explaining the medium of comics and its uses in a comic style (see Figure 2 for reference).

Also as free giveaways a flip book about the beginning of life (“Zellen schlagen Wellen”) and several postcards were created by Nadja Wostry, member of the comic team working at the Teaching Center.

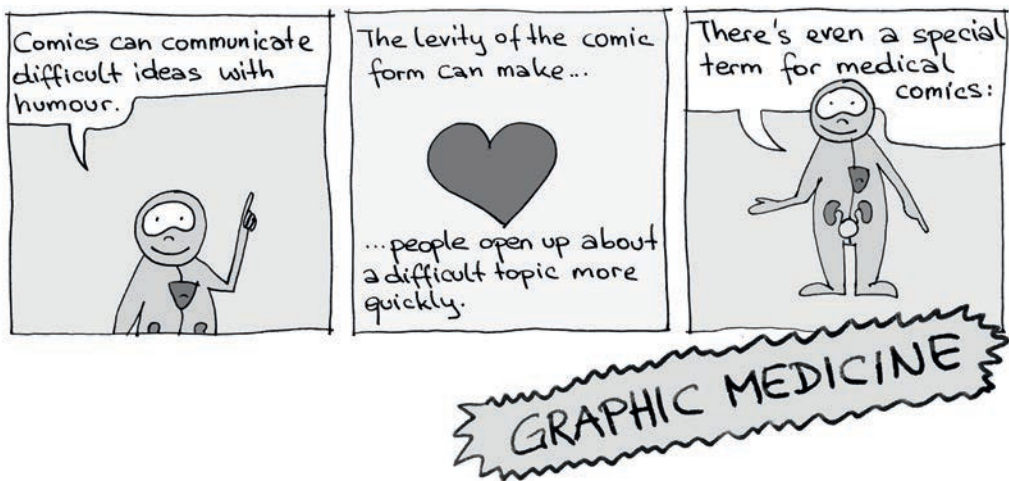


Fig. 2 Example of a medical comic; copyright of Barbara Pirker.

Exhibition art – action – attitude/borders

The second exhibition, which ran from November 2021 to June 2022, explored the concept of borders in medicine. The exhibition delved into the subjective and objective borders that individuals encounter or experience. The exhibition aimed to answer several questions, including the limits that medical staff face, the boundaries that patients and their families face, as well as therapeutic limitations. The exhibition also examined the boundaries between life and death and the spatial boundaries experienced in hospitals. Narrative Medicine was the focal point of the interactive area. The continuation of the comic booklet from the previous exhibition also addressed issues related to Global Health.

Again a brochure in German and English was published and a “Malbuch” (“drawing book for medical students and physicians”) was created by members of the Teaching Center as a special free giveaway containing creative tasks on problem areas in everyday medical life.

Exhibition art – action – attitude/pain

The *Art – Action – Attitude* project concluded with an exhibition titled “Pain” (November 2022–June 2023), which addressed the ubiquitous experience of pain in its various forms - physical, psychological, and social. The exhibition aimed to explore the factors contributing to pain and how it can be managed. Using MC to depict pain allows for a more accessible and relatable portrayal of this complex topic. The exhibition also touched on global issues such as world weariness, cultural dif-

ferences in pain management, and the impact of poor pain management on patients. Three panels were dedicated to reviewing the three exhibitions and their related initiatives, including scientific publications. Additionally, a third comic booklet on the history and management of pain, including global access to pain medication, was published (see Figure 3 for reference).

We also continued of publishing a brochure in German and English and several postcards as free giveaways.

Does it also work for teaching purposes?

The potential of MC as a teaching tool is evident, as demonstrated by their current use in two compulsory courses, each with about 650 students per year, to explore potential challenges in future medical fields. These courses incorporate MC and offer medical students the chance to contribute their own drawings. In fact, the last two exhibitions included work from medical students, and feedback indicated that this artistic approach in a medical curriculum was unexpected but widely accepted and suitable for exploring selected topics (ADAMIDIS *et al.* 2022). For teachers, MC offer a valuable teaching method, particularly in a blended learning setting, by providing a comprehensive and time-intensive analysis of students’ contributions, prompting them to visualize situations encountered in daily practice and to discuss possible solutions. In the end, a well-grounded assessment based on challenging topics may be conducted to gauge learning outcomes. MC are effective in bridging the gap between theoretical teaching and clinical practice.

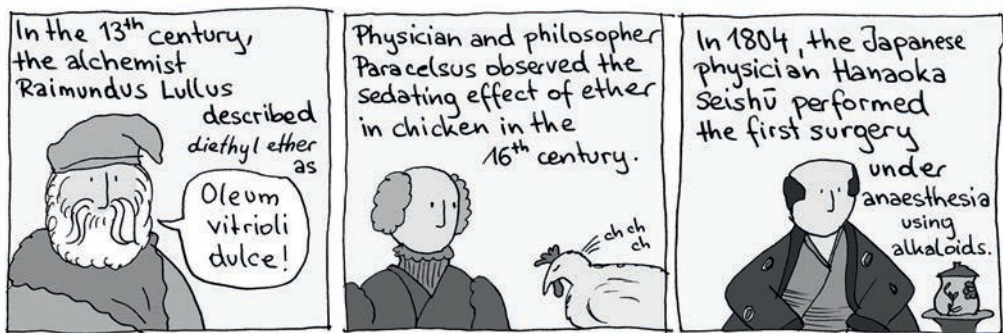


Fig. 3 Extract from the booklet *Pain*, 2022, page 7; drawings by Renate Mowlam (www.renatenwurf.at); adopted in black/white for *Curare*.

In September 2023, the Federal Ministry of Education, Science and Research awarded the Ars Docendi Recognition Prize for Excellent Teaching at Austrian Universities 2023 in the category of Learning Outcome-Oriented Teaching and Examination Culture for the project "... When Words Are Not Enough"/ Medical Humanities: Creating Space for the Unspeakable with Images".

Did you talk and write about it?

International exchange and learning is considered as a key factor to increase one's own (also the global) knowledge and understanding. We contributed to meeting dealing with teaching, art and the cultural sector.

As far as the coronavirus pandemic allowed we participated in conferences live (e.g. KOBLIZEK *et al.* 2022a) or online (e.g. KOBLIZEK *et al.* 2022b; KOLLER *et al.* 2021) as well as in invited workshops (e.g. PRASCHINGER & MASEL 2019).

Moreover, the project was supported by scientific research, leading to the publication of several works, including contributions in journals (e.g. MASEL *et al.* 2020b; MASEL & PRASCHINGER 2020c; PRASCHINGER *et al.* 2023) and books (e.g. MASEL & PRASCHINGER 2021).

On request, guided tours have been held in the exhibition area to convey the ideas, the method and medical issues. Participants have been exposed to the aim and spirit of MC.

Celebrating the finissage

The symposium "Power of Graphic Medicine" marked the culmination of the three-year project *Art – Action – Attitude*, with over 100 attendees on June 1st 2023.

It featured nine distinguished speakers from both national and international backgrounds, who provided valuable insights into their respective work, offering new and diverse perspectives on challenging topics within the field of medicine. Medicine, despite its profound importance, is not without its own set of difficulties and complexities, affecting patients, their families, and healthcare professionals alike. By acknowledging these challenges, we can initiate conversations and address them appropriately. One effective way to approach these discussions is through visual means,

such as drawings. A drawing workshop proved, that everyone can draw, can express feelings with pictures and can tell a picture story.

The end?

After the completion of the three exhibitions and the symposium, it was determined that the aim to promote and expand the potential of graphic medicine in Austria by reaching a broad audience and advocating MC as a feasible strategy for daily medical practice had been accomplished. The exhibitions successfully engaged a large number of people, and the accompanying brochures and booklets are expected to have a lasting impact on the initiative. Presently, there is a diverse collection of MC covering a range of subjects and perspectives, encouraging discussions and inspiring new drawings. Moreover, this access to MC invites individuals to express their thoughts, emotions, and experiences on paper. The strength of this access lies in the variety of viewpoints presented to viewers, drawing attention to neglected issues and focusing on crucial details while allowing room for individual perceptions. Ultimately, this fosters a collective dialogue on difficult subjects (HOUTS *et al.* 2006).

Feedback from the symposium gave rise to the idea to subsume various initiatives across Europe, maintain the exchange and keep going. Although project *Art – Action – Attitude* concludes here, we remain open to the possibility of continuing this initiative.

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Two and a Half Years of IMHAR

Report from the Institute for Medical & Health Humanities and Artistic Research (IMHAR)
an Affiliated Institut of University of Applied Sciences and Arts, Ottersberg, Germany

CÉLINE KAISER

Two and a half years of IMHAR – how can the work of the Institute for Medical & Health Humanities and Artistic Research be summarised so far? A concrete example may serve as an indication of the aims and topics we pursue and the way in which we work. A few months ago three members of IMHAR, ANGELA ALVES, MONIKA ANKELE and CÉLINE KAISER, were invited to the international and transdisciplinary workshop *Art & the Critical Medical Humanities: Confabulations X Health & Care* led by FIONA JOHNSTONE (Durham University, UK), ALLISON MOREHEAD (Queen's University, Canada) and IMOGEN WILSHIRE (Lincoln University, UK) at the Royal College of the Arts, Battersea, London. There the three presented their collaborative project “Lying in: Bed”, which will be published in 2025 in Bloomsbury's *Critical Interventions in the Medical and Health Humanities* series together with other together with other works that emerged from these “confabulations”.

Lying in bed seems to be an everyday situation. It seems even more obvious that sick people lie in bed. Being ill and lying in bed – hospitals and hospital beds are closely connected, one without the other hardly imaginable. The bed, one might think, offers itself for lying down as part of the interactive process between actors, material objects and environments. On closer inspection, however, it becomes clear that beds always unfold a normative dimension that prescribes ‘correct’ handling and leads to deviations – of a physical, cultural, psychological or social nature – being sanctioned or preventively suppressed. In this respect, beds are by no means as ‘innocent’ as they might appear. Even when they are located in private spaces and are claimed in the modern age as a symbol of privacy, as a place of escape in the face of social demands on the individual. Ideas of normal, productive or sick bodies and behaviours flow into the settings and material objects as well as socio-cultural prac-

tices. Who is lying in bed and who is not, who is in a horizontal position and who is looking at it from a vertical perspective, is always the result of structures of action and power, which are simultaneously established by relations between environments, bodies and objects. The extent to which medical concepts, cultural meanings and social codes refer to the bed as an agent in this way and use it to create and negotiate complex situations is the subject of a project initiative that has emerged from a collaboration between members of the Institute for Medical & Health Humanities and Artistic Research (IMHAR; www.imhar.net).

Under the title “Lying in: Bed”, the choreographer and crip artist ANGELA ALVES, the historian MONIKA ANKELE and the literary and cultural studies scholar CÉLINE KAISER came together to investigate the intricate relationships that human bodies enter into horizontally - with objects and the environments that surround them, as well as with medical therapies and socio-political interpretations. ANGELA ALVES is a Berlin-based choreographer with a sick nervous system, and an artistic collaborator in the project team of Claire Cunningham's professorship at the University of the Arts in Berlin. In her performance and sound installation *REST*, ANGELA ALVES invited people to lie down in her own bed and talk about lying in bed as an act of care, surrender and even an act of rebellion. Visiting her art project, you can also lie in her bed and listen to the sound installation where you can hear the voices of three women lying in bed, talking about overcoming guilt and shame, and enjoying inefficiency. These dynamics not only take place in the cognitive space where meanings are negotiated, but also take place much more subliminally on a sensual, physical level. For example, a horizontal position can also support or bring about a sense of the body that goes hand in hand with feeling ill. MONIKA ANKELE, Professor of the History of Med-

icine and Medical Museology at the Charité - Universitätsmedizin Berlin, examined the practice of being put to bed and staying in bed in the context of the history of psychiatry, using the example of the introduction of bed treatment at the end of the 19th century. Ankele is interested in unfolding the interplay of spatial arrangements (the bed) and sensory perception (feeling sick) that should convince the patient to feel sick. The fact that doctors' perspectives on bodies lying down can also be permeated by social, normative, politically and ethically problematic ideas becomes particularly tangible where the clinical context fades into the background: in literature. The story of Oblomov, the eponymous main character of the novel by IVAN GONČAROV from 1859, is about lying in bed and getting up, being horizontal and then rising into the vertical. CÉLINE KAISER follows this figure of literary and medical history, tracing the novel from its reception in the 19th to the 21st century, which sometimes appropriates OBLOMOV as a symbol of feudal decadence, sometimes as the eponym of a clinical syndrome, sometimes as a refusal of the neoliberal idea of self-improvement. The attributes associated with the figure of OBLOMOV, especially by physicians and psychologists, and the implications they bring to light in the transfer of the literary figure to a clinical patient illustrates a hopelessly overdetermined entanglement of verticality with productivity and the horizontal with passivity, asociality and a refusal to be productive.

This outlined project continued in content and structure what motivated the founding of IMHAR, the International Association for Medical & Health Humanities and Artistic Research, e. V. (<https://www.imhar.net/association/>) in 2020, which is to say in combining approaches from Medical & Health Humanities and artistic research it have aimed to develop and advance innovative perspectives on ways of perceiving health and illness in a productive and experimental way.

Some of the founding members had already made artistic or scientific contributions at the international conference *Material Cultures of Psychiatry* at the University Medical Centre Hamburg-Eppendorf, which was conceived by MONIKA ANKELE and BENOÎT MAJERUS. The opening ceremony of the *Institute for Medical & Health Humanities and Artistic Research* (IMHAR) on 25 March 2022, which emerged from our association, has been co-direct-

ed by MONIKA ANKELE and CÉLINE KAISER since its foundation.

Since then, the *Institute for Medical & Health Humanities and Artistic Research* is a space and forum for transdisciplinary approaches and research practices. It initiates, designs, and conducts research projects, builds project-related collaborations and works in multi-perspective teams to further develop research and communication strategies that are suitable for communicating its research findings beyond the scientific community. The Institute aims to provide a space for research and discourse that is open to diverse perspectives. It represents a critical and decidedly cultural-scientific position in the field of Medical & Health Humanities, as called for in particular by WILLIAM VINEY, FELICITY CALLARD and ANGELA WOODS. Cultural forms, material cultures, artistic practices, corporeality and sensual perception of all actors involved in the context of medical cultures are at the centre of the research questions to be addressed in the Institute's projects. In our view, a combination of artistic, cultural studies and historical investigations strengthens research processes that may start from subjective dimensions of perception and experience but aim at a critical exploration of the cultural dimensions of health and medical cultures. Here, productive connections expand to disability studies, to critical reflections on racism, to questions of gender studies, to name just a few of the neighbouring fields of research in cultural and social sciences. Common to many projects of Critical Medical and Health Humanities is a programmatic openness to activist perspectives and a participatory inclusion of the patient perspective in research work.

We assume that by linking the research approaches of Medical & Health Humanities with those of artistic research, a 'different', situated and embodied knowledge can be applied, tested and critically reflected in research and communication processes. By linking such approaches with the modes of perception and cognition characteristics of artistic research, aesthetic, medial and embodied dimensions of the perception of being healthy and being ill can be explored, thematised, brought into play and questioned, as well as the resulting social and sensual experiences of inclusion and exclusion. The interplay of artistic and cultural studies research methods can thus contribute to

relating sensual perception and sense-making in different medical contexts and make them fruitful.

Our concerns are not only reflected in our projects and collaborations. They become tangible in the composition of the people who are committed to the founding of the research institute and who, as members of the association, have jointly developed a lively culture of discussion and openness to transdisciplinary issues: Our members include artists, cultural scientists, medical historians and activists, or to put it another way: People who productively cross the boundaries between these fields in their scientific and artistic practices.

Our main fields of interest are also evident in the series of events we run with external guests. In addition to the “IMHAR on Tour” event format, within which the Lying in: Bed project took place, we have developed three other event formats in which we offer several meetings per semester: the “Reading Room”, the “Colloquium” and the “Salon”. These events take place in a digital space, which makes it possible to participate from different locations around the world. The “Reading Room” is used for joint reading sessions and discussion regarding basic texts and current contributions from the fields of Medical & Health Humanities and artistic research. The colloquium offers members of the Association the opportunity to present project ideas in a protected space and to develop them further through dialogue with participants. In recent semesters, our colloquium has also enabled us to exchange ideas and network with other initiatives and institutions from the field of medical humanities, such as the Medical Humanities Research Centre in Innsbruck. In our digital salon, we invite artists, researchers and activists who inspire our thinking and our work with their projects, thinking and approaches. For example, we hosted the Viennese artist BARBARA GRAF, who presented her artistic research work on the perception and visualisation of pain from the perspective of a person suffering from multiple sclerosis. The Flensburg artist ELKE MARK presented her artistic research work on the sense of touch and sensory knowledge. Under the headline “Haptic visualisation”, we invited STELLA BOLAKI from the University of Kent and the physician and artist KATHARINA SABERNIG from Vienna. BOLAKI presented her project on Artists Books in the Medical Humanities and KATHARINA SABERNIG gave us an insight into her

“Knitted Body Materiality”. Another double feature took place under the title Designing Sensuous Spaces, where VICTORIA BATES and REBECCA FLEETWOOD-SMITH from the University of Bristol, were invited to present their project “Sensing Spaces of Healthcare”, and the Amsterdam based artist JENNIFER KANARY NIKOLOV(a), who in her presentation shared insights into “Labyrinth Psychotica. The Wearable”, a psychosis simulation VR project, and the subsequent follow-up project “The Anoiksis Experiment”. Other guests in our salon were RUTH ANDERWALD and LEONARD GROND from the Angewandte in Vienna, who spoke about Dizziness. Two researchers spoke in our salon about film & psychiatry: MIREILLE BERTON from Lausanne presented her SNSF project “Cinéma et (neuro)psychiatrie en Suisse: autour des collections Waldau” (2021-20125) and the Bremen film scholar TOBIAS DIETRICH gave insights into his research on film and mental illness. This year we also hosted FIONA JOHNSTONE from Durham University, who made a presentation about the work of the Visual and Material Lab that she currently leads as part of the Discovery Research Platform for Medical Humanities at the University of Durham (2023-2030). And MONIKA PIETRZAK-FRANGER from the University of Vienna presented a joint project that she realised with the Viennese photographer PETER MAYR concerning “Living with Long Covid. Interviews and Photographs”. YLVA SÖDERFELDT and ERIKA SIGVARDSDOTTER, Director and Coordinator, presented their Center for Medical Humanities at Uppsala University (Sweden) as well as new formats of collaboration in the course of the Artists in Residence Programme, which started in 2023 with the artist ANNA ODELL. In the next few months we expect a presentation by the Berlin artist and psychologist KIRSTIN BURCKHARDT about her work (Relationships, on 8th November 2024, 4 p.m.). And on 6th December 2024, 4 p.m., we look forward to a contribution by the artist SASHA BERGSTROM-KATZ “On the Subject of Tests: Performing with Objects”. On 24th January we are expecting SOPHIE LEDEBUR in our colloquium to discuss the Medical Collection of the University of Zurich. If you are interested in attending one of these events, please do not hesitate to contact us at anmelden@imhar.net. Of course, we are also happy to welcome new members! (see <https://www.imhar.net/association/>).

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Tibetan Anatomical Terms in “Knitted Body Materiality”

Report from a Project at University of Fine Arts Vienna, Austria

KATHARINA SABERNIG

Introduction

“Knitted Body Materiality” is an art-based research project started in April 2022, supported by the Austrian Science Fund and undertaken at the University of Applied Arts Vienna, through the “PEEK” grant which is one component of the FWF’s portfolio (Programm zur Entwicklung und Erschließung der Künste, PEEK) and allows for the development and evaluation of an artwork for four years in manifold ways. This report sheds light on the initial thoughts and ideas which led to the creation of the first knitted anatomical objects rather than any current artistic outputs such as the development of anatomical theatre performances, animated videos or the exhibition of photographs and objects. Aspects of my artistic approach regarding ethical questions and the materiality of three-dimensional anatomical representations can be found in SABERNIG (2022, 2023, 2024) and will not be discussed here, instead the circumstances of the initial thinking of the project will be described. The idea of “knitted anatomy” is closely related to my early research projects on Tibetan medicine and terminology, as well as the visualisation of medical content. In particular, the project on the anatomical achievements of the physician and surgeon LOBSANG CHÖDRAK (*Blo bzang chos grags* (1638–1710?); FWF 26129-G21, September 2013–August 2017) in the context of the global history of anatomy (SABERNIG forthcoming) was nascent for my thoughts on the materiality of anatomical presentation. During that time, I delved deeply into the published world of Tibetan anatomical terminology and created a database on “Tibetan medical terms” described in more detail below. I started to analyse the development of Tibetan anatomical terminology in historical and contemporary medical works and anatomy atlases. With regard to modern medical terms,

Tibetan scholars and scientists have done extensive work to find and introduce adequate biomedical anatomical expressions in the first decade of the new millennium. This enormous intellectual achievement has not yet been reflected in any Western dictionary. Unfortunately, the Tibetan and Chinese-Tibetan atlases use neither Latin nor English wording. Most Tibetan scholars know biomedical knowledge only via Chinese-Tibetan translations. A bilingual Tibetan-Latin or Tibetan-Englisch medical atlas, showing a clear connection between depicted anatomical structures and internationally binding medical nomenclature, does not yet exist. The only publication that comprises the international nomenclature is the trilingual *Chinese-Tibetan-English modern medicine dictionary* (CTE 2011), but the publication does not contain any images or graphic representations and does not provide an English or Tibetan index of terms. This led me to the intention to create a Tibetan-Latin (English) anatomical atlas that aims to close this gap by communicating anatomical terminology visualised in the playful and colourful styles we know from anatomical thangka paintings.

An examination of classical tibetan medical terms and the coining of new anatomical terms

Discussions on the standardisation of anatomical language have a firm tradition, both in modern biomedicine and in Tibetan medicine. A historical process of standardisation took place in Tibet in the seventeenth century which resulted in a set of thangka (scroll) paintings accompanying the *Blue Beryl*, Tibet’s most authoritative commentary to the Four Tantras medical treatise (see also BARBARA GERKE in this issue). The classical paintings

present and localise many anatomical terms given in various classical Tibetan texts. In the eighteenth and nineteenth centuries there were no significant developments in anatomical knowledge, only in the early twentieth century and with the revitalisation of Tibetan medicine from the mid-1980s onwards when a vibrant period of publishing activity began, which culminated around 2012 (cf. BALK 2016).

With the integration of biomedical language in the training of Tibetan medics, several elaborate bilingual anatomy atlases in Chinese and Tibetan language were produced in China. A question arose regarding the extent to which these publications would integrate classical terminology or coin new terms adapted to biomedicine, as well as how anatomical structures and educational content would be visualised. Some anatomical illustrations are based on the colourful, sometimes humorous or playful traditional style of depiction, others use conventional biomedical depictions or choose photos obtained through dissection or computer tomography. What is currently still missing, is a reliable reference of modern Tibetan anatomical language to the *Terminologia Anatomica*, the internationally authoritative directory of terminology (WHITMORE 1998).

In the early years of the twenty-first century Tibetan scholars of traditional and biomedicine made considerable efforts to translate biomedical anatomical terminology by coining new words in the Tibetan language or translating Tibetan medical terms into Chinese or English. At least four anatomy atlases were published using different terms for specific anatomical structures and a Tibetan medical dictionary including several anatomical charts were edited, these publications will be described in more detail below. The diversity of terminology and visualisation prompts several questions: 1) How far and in which way do these publications integrate classical Tibetan medical terminology? 2) Which kinds of terms and names have been used to coin new terms adapted to biomedicine? 3) How were the anatomical structures and educational content visualised, and finally, 4) since a reliable reference of the modern Tibetan anatomical language to the internationally authoritative directory *Terminologia Anatomica*, is still missing: how could Tibetan terminology be linked with the international standard and

in which way could it be visualised? Preliminary considerations regarding question 1) and 2) have been published in SABERNIG 2017b, 2019.

To answer these questions, I could rely on the results of my previous projects on allegoric medical tree paintings structuring the content of the *Explanatory Tantra* (the second of the *Four Tantras*). Herein I had already investigated classical medical terms (FWF-Project 22965-G21) because in most cases in the tree metaphor a single leaf of a tree's branch symbolises a certain medical term (cf. SABERNIG 2017a). In the following project I analysed classical anatomical terms that occur in the commentaries to the *Explanatory Tantra* (FWF-Project 26129-G21), with the intention of building a sound basis for undertaking the task of building the database named *Tibetan Medical Terms*. I started to collect a variety of possible identifications of Tibetan *Materia Medica*. The database contains medical terms described and identified in no less than thirty relevant sources, including general and medical dictionaries, glossaries, historical and modern subject-specific literature such as pharmacopoeias, anatomical atlases, and other publications on Tibetan medicine. The aim was not to find a standardised definition of these terms in a normative sense, but to document the plurality of the suggested translations. The database is not only a good starting point for my studies on the extent to which classical anatomical terms can be found in modern atlases, but is also publicly accessible to everyone. Hosted by the East Asia Department of the Staatsbibliothek zu Berlin it was first made accessible for users in 2014 via *CrossAsia*, an internet portal focused on Asian studies offered by the library (web address: <https://crossasia.org/service/crossasia-lab/tibetische-medizin-termini>). A software tool was developed in the East Asia Department and implemented to automatically convert Tibetan keywords into original Tibetan script. This has the desirable advantage that the database may also be used and appreciated by Tibetan scholars in the script they are familiar with.

With the further growth of the database, it became clear that it should not only generate terms that occur in classical works. Traditional Tibetan medicine continues to be practiced in modern society and is a pillar of regional health systems in various parts of Asia. I decided to not only docu-

ment historical medical terms, but also to present developments and to understand the formation of new terminology as Tibetan medicine encounters modern biomedicine. Therefore, the evaluation and documentation of modern anatomical terms which relate to biomedical structures as presented in recently published anatomical atlases in Tibetan or in bilingual Chinese-Tibetan editions became substantial. Largely unnoticed by the international field of research on Tibetan medicine, contemporary Tibetan scholars have made significant contributions to the development of names for modern biomedical anatomical structures in Tibetan language. Several books containing traditional as well as modern anatomical depictions and several dictionaries have been published (for more information on these and earlier anatomical sources see: SABERNIG 2017b: 93-100). Compared to publications in other non-Chinese minority languages in China, this publication of anatomical literature is exceptional and draws on a long Tibetan tradition of empirical anatomy (e.g.: GYATSO 2015; SABERNIG 2016, 2017b). Tibetan translation projects are promoted by the Chinese state and are a sign of the professionalisation and integration of Tibetan medicine into the health system. With the help of the newly published atlases and a number of modern reference books it became possible to trace the anatomical terms as they have changed over time and to check whether they are integrated into modern medical vocabulary. The starting point was historical thangka paintings, then I selected four elaborately edited anatomical atlases and two dictionaries for my broader comparative survey from the sources in the database. The atlases are: TING-VDZIN 2007; PAD-MA-RAB-BRTAN & SANGS-RGYAS-VBUM 2011; NYI-MA-TSHE-RING & MIG-DMAR 2012; and MKHAS-GRUB 2012 – the dictionaries are trilingual *Chinese-Tibetan-English modern medicine dictionary* (CTE 2011) and a *Dictionary of Tibetan Medicine* (BST 2006).

When looking at such recent atlases and similar publications, they have in common that the depicted structures refer to modern anatomy, but the related Tibetan terms are not linked to the international standard of human anatomical terminology. Only a person who can read anatomical maps as well as Tibetan script (or Chinese) is able to identify the terms. The only publication that comprises the international nomenclature is the

trilingual *Chinese-Tibetan-English modern medicine dictionary* (CTE 2011). The dictionary is intended to establish a Tibetan standard for modern biomedical terms based on Chinese keywords. It was compiled by a large working team involving various Tibetan institutions. I call the anatomical terms contained in this comprehensive medical dictionary *Terminologia Anatomica Tibetana* as it is intended to be a new standard of Tibetan anatomical language. During my staying in Xining I was told that the anatomy atlas published by PAD-MA-RAB-BRTAN and SANGS-RGYAS-VBUM (2011) is largely identical in its terminology to the standard *Terminologia Anatomica Tibetana*.

Preparation of a colourful bilingual tibetan-latin anatomical atlas

After examining the state of publications, I felt a Tibetan-Latin or Tibetan-English anatomy atlas visualising modern anatomical terminology in Tibetan language would be a desideratum. In my opinion the study and translation of modern anatomical terms into Tibetan and their identification according to internationally binding nomenclature (*Terminologia Anatomica*) is an important contribution to the professionalisation and globalisation of Tibetan medical practice. My aim was to create a helpful point of reference for physicians who want to deal with Tibetan medicine, but do not have direct access to Tibetan original texts due to a lack of sufficient language skills but are willing to learn the language. In addition to this, such a bilingual atlas offers Tibetan scientists unbiased access to English anatomical terminology. Tibetan scientists have done much work to introduce biomedical and anatomical vocabulary to the Tibetan language, but unfortunately no Tibetan-Latin or Tibetan English anatomy atlas has been produced. For English-speaking practitioners of Tibetan medicine, such a publication would be very helpful. So far, there are only Tibetan or bilingual Chinese-Tibetan publications that present medical knowledge along with anatomical illustrations, which are so important for understanding the topography of the body. My findings showed that the basis for the planned anatomy atlas should be the *Terminologia Anatomica Tibetana* found in the atlas of modern anatomy edited by PAD-MA-RAB-BRTAN and SANGS-RGYAS-VBUM (2011), which

I started to include in the database. The next question was how to visually represent the anatomical structures? One possibility was to simply add Latin or English terms to one of the modern atlases introduced so far. Not only because of copyright issues I decided to go in a different direction. As a result of observing publications over many years, I had the strong sense that the visualisation should be colourful and playful, in a style similar to the *thangka* illustrations. The images should be pleasing to the viewer, the visualised internal structures should evoke interest in the body and capture the imagination – not evoke disgust. Due to the Tibetan tradition of tantric meditation by visualising internal channels this point is especially important, but also in a general European context of medical and health humanities it is important to develop a comforting idea of oneself.

The knitted anatomical models are not only didactic tools suitable for the presentation of Tibetan-Latin anatomical terms, but also have great potential to demonstrate the anatomy of tabooed body regions to a non-scholarly audience. In presenting prototypes of my work, responses were surprisingly positive on several occasions at conferences and university lectures, but also during lectures in front of Tibetan-speaking audiences in Qinghai Tibetan Medicine Hospital, Lhasa and Beijing. The knitted structures tend to have the opposite effect to the reflex of revulsion: as far as I can tell from my preliminary presentations, the audience as a rule find these anatomical depictions both pleasant to look at and thoroughly informative. While trying to understand the show-cased structures, the viewers' attention increases and their faces express comforting familiarity instead of visceral disgust (cf. SABERNIG 2024). In Lhasa, in 2016 I held a lecture on the history of anatomical depictions during which I presented images of knitted organs labelled in Tibetan script. Afterwards, local physicians told me that Tibetans feel the same visceral disgust when viewing 'realistic' anatomical images, therefore they prefer colourful images involving a sense of humour as presented in the illustrations to the *Blue Beryl* (e.g. PARFIONOVITCH 1992 or the book by TING-VDZIN's 2007). I became convinced that a bilingual Tibetan-Latin atlas would close a gap in medical didactics if the structures of the human body were presented in both ways, on the one hand colour-

ful, pleasing, and involving a sense of humour, and empirically accurate on the other. However, the project was never started because the reviewers' report did not result in funding. I continued to work on "knitted anatomy" without any funding and developed it in a more artistic direction rather than as a didactic aid for Tibetan medical terminology. Sensory perception in the context of medicine and arts, including the history of European medicine, came to the fore of considerations.

Against the background of the history of anatomical representation, which is connected to controversial ethical discussions with regards to gaining and representing human material the knitted texture has didactic, ethical and aesthetic advantages. Although anatomical description without any visual aid is a widespread genre of pre-modern medical texts, in contrast to other medical fields, topographic anatomy is highly reliant on visual representation. Neither historical visual representation nor modern techniques represent human bodily structures as they can be observed by the human eye during dissection or surgical intervention. The use of the colour red for arteries, blue for veins or yellow for nerves is an international convention which is only partially based on "real" impressions. Although scientifically correct and empirically verifiable, anatomical images usually remain symbolic. Depending on their purpose, they are sometimes designed as metaphors such as the illustrations presented by FRITZ KAHN (cf. GÜNTHER 1923; SAPPOL 2017).

One reason for depicting the human body in an idealised manner is that spontaneous visceral disgust can arise. The unvarnished sight of a dead body disgusts or distracts many viewers; a natural reflex of revulsion can be regularly observed, particularly on the part of a non-medically educated audience. To divert disgust anatomical images or three-dimensional models such as the famous anatomical wax models displayed at the Viennese Josephinum are often presented in an aestheticized, idealized manner, using striking and vivid postures (e.g.: WINKELMANN 2003: 45f.; HENDRIKSEN 2015, SAPPOL 2017: XI). To avoid disgust and emphasise the pictorial structure many modern atlases or other illustrative material present structures in a minimal way by omitting all structures of less importance or by using transparent and glassy silhouettes with a clean or even

sterile appearance. The type of information and representation depends on cultural, ethical, philosophical, budgetary, gender-specific aspects as well as the question of to whom the anatomical illustrative material is addressed. In the context of *dealing with the disgust evoked by practicing anatomy*, MARIEKE HENDRIKSEN (2015: 12) writes about aesthesis: *This combination of sensory perception and a sense of beauty necessarily also includes the development of strategies to deal with the visceral disgust encountered in the process of gaining anatomical knowledge* (HENDRIKSEN 2015: 205).

Anatomical and even more pathological presentations have yet to consider another significant psychological aspect: in perceiving anatomical representations, the viewer not only reflects on the scientific knowledge or skilled craftsmanship behind an image, but also identifies with the seen structure and links it to their own material and mortal body. This might be exciting for a healthy individual but is demanding in the case of pathology (cf.: SCHNALKE 1999: 18; SCHNALKE and ATZL 2012: 25f.). During the corona pandemic, I had the impression that a lot of the resistance against measures, vaccination and the threat posed by the virus was a defence against the imagined corresponding processes in one's own body. I decided to visualise different aspects of the pandemic in knitted form, using a material associated with warmth, care and protection, rather than purely scientific language that is difficult to understand and evokes fear and disgust. The images were published in several magazines and on my website under the heading 'corona extra'. The picture 'Hope' is one of them and was the subject of the AGEM conference.

In my revised research application in affiliation with the University of applied arts all these considerations played a decisive role and in March 2022 the project was granted. The funding approval gave me the opportunity to examine the use of the knitted objects in various artistic formats such as film, photography, theatre or exhibitions. An anatomy atlas is also included. Once the atlas is created, the last step is to connect the entries of the database with the labelled anatomical terms in order to publish a special edition of Tibetan-Latin terms. This makes it possible to accomplish my

long-held wish to visually link Tibetan anatomical terminology with its international equivalents.

Notes

- 1 This research was funded in part by the Austrian Science Fund (FWF) [grant DOI 10.55776/AR705]. For open access purposes, the author has applied a CC BY public copyright license to any author accepted manuscript version arising from this submission.
- 2 <https://crossasia.org/en/service/crossasia-lab/tibetische-medizin-termini/>.
- 3 <https://www.knitted-anatomy.at/corona-extra/>.

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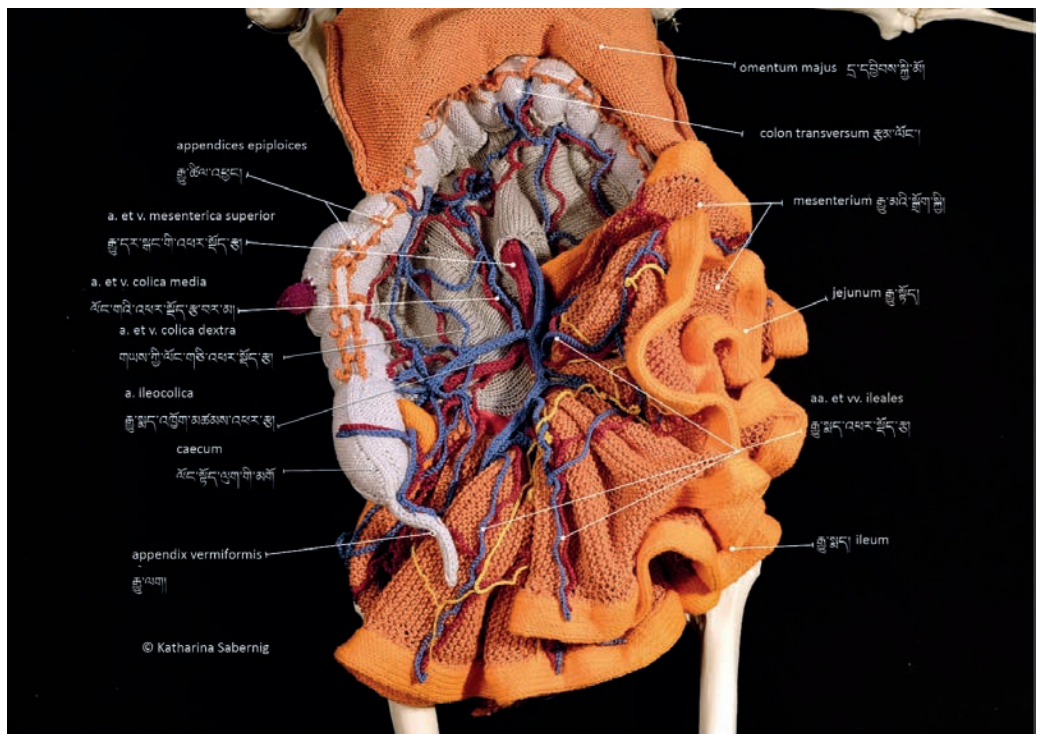


Fig. 1 Small and large intestine with Tibetan and international terminology



Katharina Sabernig is project leader of the FWF project “Knitted Body Materiality” (doi: 10.55776/AR705) at the University of Applied Arts Vienna and studied medicine and cultural anthropology in Vienna. In her previous projects she focused on anatomical illustrations, visualized medicine and Tibetan medical terminology, about which she has published extensively. Inspired by the diversity of anatomical representations and the ethical issues involved, she began knitting anatomical objects in 2015 to find answers to various questions regarding ethics, materiality and perception of anatomical presentation. In her current project, the three-dimensional textile creations are not only exhibited, but also presented through photography, video animation and performative anatomical theater.

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Comparative Guts – Exploring the Inside of the Body Through Time and Space

Report on a Conference organized by the Cluster of Excellence ROOTS of the Christian-Albrechts-Universität zu Kiel at Kunsthalle Kiel, 7–9 June 2023

KATHARINA SABERNIG

The conference was part of a carefully planned longer term project which aimed to investigate the visualisation of the inside of the body from a comparative perspective. A year before the hybrid in person event took place more than thirty visual artists, textual historians, medical anthropologists and archaeologists were invited to several online meetings by CHIARA THUMIGER and ANGELIKA MESSNER (both from Kiel University, Cluster of Excellence Roots). This was in order to work collaboratively in creating an online exhibition to present human guts from various angles. The project was created as a platform for interdisciplinary dialog and partnership with a diverse and inclusive perspective. It was part of the sub-cluster: ‘Knowledge’, under the Cluster of Excellence: ‘Roots’ at Christian-Albrechts University in Kiel funded by the German Research Foundation (Deutsche Forschungsgemeinschaft: DFG). With this multidisciplinary approach, it did not take long before lively debates about the function, definition and ethical or emotional significance of our guts would ensue. The differing perspectives were brought together under the design of Christoph Geiger, who created a wonderful digital exhibition that has been available online since spring 2023 (<https://comparative-guts.net/>). It can be regarded as a collection of regional histories and a reflection on different frameworks endorsed by the conference program with manifold contributions. The conference turned out to be a celebration of what has already completed and is ready to be shown to a broader public. It was inclusive not only with regards to perspectives but also our senses. On the final day, specially made tactile panels with historical or contemporary representations of guts were set up so that visually impaired people could also read more about the topic, and

scents which imitated the smell of ancient rituals involving animals were presented to the attendees. This part was supported by Christian-Albrechts University (Diversitätsfonds der Christian-Albrechts-Universität zu Kiel). In the meantime, a printed catalogue with all contributions has been published.¹ The following report is based on my own conference transcript and is complemented by the texts written and published by the presenting authors.

Wednesday, June 7

In her presentation, entitled “An Example of 17th-century Sino-European Cross-Cultural Medical History”, MARTHA HANSON (Max Planck Institute Berlin, Erlangen Divination) selected five images held in the Staatsbibliothek zu Berlin, two images were taken from Chinese medical manuscripts depicting two different side views of the body. Another three images were shown representing European interpretations of the first two images (1682 Specimen Medicinae Sinicae Frankfurt). The images are connected with the first translation of formulas and Medicinals: A 17th century *Materia medica* traveled from China to Europe held in the Staatsbibliothek which apparently is not the original but a later print. She showed the complexity of its reception and historical transfer to Europe and introduced the translations and hand written texts of historical figures involved such as Polish MICHAEL BOYM (1612–1659), FLEMISH PHILIPP COUPLET (1623–1693), SHEN FUZONG (1658–1691) Acadmie Naturae Curiosorum (future Leopoldina), ANDREAS CLEYER (1634–1698) or German SEBASTIAN SCHEFFER (1631–1686). (<https://comparative-guts.net/an-example-of-17th-century-sino-european-cross-cultural-medical-history>).

BRIGITTE SONNE (University of Copenhagen) and ULLA ODGAARD (independent) gave an historical overview of the history of the East Arctic region and discussed the special significance of entrails in Inuit culture in Greenland (“Greenland Tupilak Figures: Arctic archaeology”). Regarded as the direct ancestors of contemporary Greenlanders, Inuit hunting culture and their specialised knowledge was vital to the prevention of hunger and death. Inuit hunting utensils were not only connected to the spirits, but they were also often made of guts. For example a hunting bladder made of seal skin or a hunting float or cooking pot made of a stomach. An exceptionally well made item of clothing for a girl was presented: a watertight lightweight gut skin parka made in the middle of the 18th century served as protection from wind and rain. This material was also used for adult sized underwear in the winter. Aside from these very practical tools used in the cold arctic, other objects were connected to myths and sorcery. (<https://comparative-guts.net/greenland-tupilak-figures>)

IGNACIO SANCHES (University of Warwick) stressed in his presentation “Anatomical Traditions in the Premodern Islamic World: Arabic and Persian Materials” that a prominent feature of anatomy and human representation in the medical Islamic World included the question of dissection. IBN AL-NAFIS’ (1213–1288) brain ventricles were presented as well as HUNAYN IBN ISHAQ’s (808–873) diagram of the visual system which is one of the earliest of its kind. In connection to Chinese medicine, an early example of the transfer of medical knowledge was shown: the Persian Translation from Chinese: the *Tansūqnāma* commissioned by Mongol vizier RASHĪD AL-DĪN in 1313 (Istanbul MS Aya Sofia). European influences and the origin of the „Fünfbilderserie“ of MAṢŪR IBN ILLYĀS (14th; Teheran MS Majlis 7430) were discussed in comparison with images from the Benedictine cloister of Prüfening (dated 1158). They illustrate arteries, veins, muscles, bones, nerves of a human being and might have served as templates for Tibetan Medical Thangkas. (<https://comparative-guts.net/arabic-and-persian-materials>)

TAWNI TIDWELL (University of Wisconsin) & KATHARINA SABERNIG (University of Applied Arts) focused on “Tibetan medicine (8th to 17th century) including contemporary knitted artwork

interpretations (early 20th to 21st century)”. Tibetan anatomical representations became widely known with the publication of a set of 79 medical thangkas (scroll paintings). TIDWELL introduced the history and significance of these original, colourfully elaborated paintings from the seventeenth century commissioned by SANGYÉ GYATSO (1653–1705), who was the regent of the Fifth Dalai Lama (1617–1682). Many of the anatomical depictions refer to either anatomical structures mapping medical terms or therapeutical interventions regarding intestinal ailments. The author of this report, SABERNIG, spoke about the spread of anatomical knowledge to the northern regions. In the early decades of the 20th century in Mongolia and especially in Buryatia, a part of Russia since the 17th century, efforts were made to adapt Tibetan body images to modern anatomy. The Buryat medical scholar Dondub Endonov (1870–1937?) authored another set of anatomical paintings (see BOLSOKHOEVA in *Curare* 39 [2016] 1).² (<https://comparative-guts.net/area-tibet>)

Modern anatomy is a child of the renaissance and started an avalanche of scientific depictions explained GIDEON MANNING (Cedars-Sinai Medical Center, Los Angeles) in his presentation on “Birth of Modern Anatomic-Pathology”. MANNING focused on new theories and data on wood blocks and engravings. Asking questions regarding where, why and who performed anatomical dissection and produced paintings. The Painting “JOHN BANISTER Delivering an Anatomical Lecture on the Viscera” (1581) was used as a visual demonstration of the connection between dissection and the text. The scene depicts the dissection of viscera with a framed copy of REALDO COLOMBO’s *De re anatomica* (1559) prominently displayed. Depictions of guts were viewed in particular contexts such as “Guts and Punishment”: the Reward of Cruelty in *The Four Stages of Cruelty* by William Hogarth (1697–1764), “Guts and Persecution” in the martyrdom of St. Erasmus, about 1430–1440 by Master of SIR JOHN FASTOLF, “Guts and Sculpture” in Andreas Vesalius *De human corporis fabrica libri septem* (1543) or “Copying guts and Vivification”: from JUAN DE VALVERDE *Historia de la composición del cuerpo humano* (1556). (<https://comparative-guts.net/birth-of-modern-anatomic-pathology>)

A completely different approach to combining text and visualisation was presented by the ATLOMY Project which creates digital 3D models on Aristotelian texts and its terminology by means of textual and visual analysis. In this project, as described by DMITRY EZROHI (Hebrew University of Jerusalem) in his presentation “Modelling as Research: Digital imaging and history of medicine”, classicists, modern anatomists and experts in 3D design and software development worked together to discover the unknown parts of these ancient medical texts. Textual analysis brought to light that the caecum is described as much larger in the ancient texts than in modern texts. It is the purpose of the project to visualise this sort of detail by means of 3D animation. It also turned out that the text reads as a description about and not of the large intestine, and reference is given to parts of other animals of a similar nature. Hands-on dissection with veterinarians allowed visual analysis and comparison with the large intestine of pigs. The project discovered that the text is based on animal analysis and described in a humanised way including physiological processes, by use of metaphor from daily life such as comparisons with pots and mugs, or food seeping through vessels and their pores like water through raw ceramic vessels. (<https://comparative-guts.net/digital-imaging-and-history-of-medicine>)

CHIARA THUMIGER (Christian Albrechts University zu Kiel and Humboldt University Berlin) took a close look at “Greco-Roman Medical cultures”. While the first documented beginning of Graeco-Roman medicine is associated with Hippocrates of Cos, the first surviving detailed anatomical works are assigned to Aristotle who studied bodily structures on non-human mammals. Even though artists and poets were interested in the internal organs hidden under the abdominal surface, medicine was not primarily interested in looking under the skin and images are hardly available. CHIARA THUMIGER presented a variety of figurative material visualising the outer silhouette of human guts: such as the marble tombstone of the Athenian physician Jason (Trustees of the British Museum, 2nd cent. CE) palpating a young patient’s belly or the Cleveland Apollo (Apollo the Python-Slayer) which portrays the outer shape of the lower abdomen. A Hellenistic terracotta figurine (Benaki Museum, Athens 3rd Cent BCE)

presents an old man with a protruding belly in a playful, even comical position. All these figurative materials demonstrate awareness of the significance of the condition of human guts. (<https://comparative-guts.net/greco-roman-medical-cultures>)

The history of the “The ancient stomachion, a Graeco-Roman gut-game” is examined in the ERC granted ATLOMY Project and was presented by MARCO VESPA (Hebrew University of Jerusalem). It is not included in the encyclopaedic and lexicographical texts explaining ancient games. The term refers to the Greek noun *stomachos* denoting the oesophagus or at least the tube between the mouth (*stóma*) and the stomach. From the available texts, an Arabic translation and a reproduction held in the Museum of Ancient Greek Technology, we know that it consisted of 14 geometric forms which can be formed to a square, this is similar to the famous game *Tangram* which consists of only seven forms. In the late nineteenth century a manuscript dated to the 10th century, was rediscovered in Istanbul which contains texts contributed by Archimedes who discussed the game from a mathematical and geometrical perspective. The name and use is still under discussion. (<https://comparative-guts.net/the-ancient-stomachion-a-greco-roman-gut-game>)

CLAIRE BUBB (New York University) focused on “Medieval Medical Sources in Latin”. The medieval period lasts from late antiquity to the early renaissance. The core region of the medical texts and images discussed was the Western Roman Empire in exchange with the Byzantine Empire. Translation of Greek medical knowledge into Latin took place at around the twelfth century, Latin translations of Arabic and Greco-Arabic material formed the basis of the European understanding of anatomy. An introduction to the history of the so called Five-Figure-Series (Fünfbilderserie) is imperative. However, the history of the illustrations of the Uterus from Musico’s epitome of Soranus’s *Gynecology* raised my attention as there are also images of pregnancy in Tibetan medical *thangkas*. The image of Guido da Vigevano’s *Anathomia* shows the forearm and lower leg with a single bone, which is another interesting parallel to Tibetan medical *thangkas*. (<https://comparative-guts.net/medieval-medical-sources-in-latin>)

CHARLOTTE DAMM (Arctic University of Norway) presented in her contribution “Hunter-Fishers of coastal Norway (5000–3000 BCE)” ancient rock art in northern Scandinavia from an archaeological, historical and religious point of view. Whilst only very few records from 9000-5000 BCE exist there is particularly substantial evidence from the time 5000 CE onwards. In the maritime sparsely populated area inhabitants lived from fishing, sealing and hunting. Rock art is found widely with individual motifs, dominated by terrestrial animals (reindeer, elk, red deer). Today many are made visible with an artificial red colour; originally they were slightly grey. The images focus on the outer appearance rather than internal anatomy, sometimes they show “life lines” to the heart, lungs and stomach. While there are no depictions of the practice of butchering, indications of world view and cosmology can be found. Comprehensive narrative scenes show terrestrial animals inhabiting both this and other worlds and blood from the nose and mouth is associated with death, but also with trances or life force. (<https://comparative-guts.net/hunter-fishers-of-norway>)

Thursday, June 8

THOMAS COUSINS (School of Anthropology and Museum Ethnography, University of Oxford) turned towards the African continent where guts are regarded heterogeneously. In contrast to Asian medicine only rare perspectives from Africa are included for comparison. The presentation started with reference to SIR EDWARD EVAN EVENS PRITCHARD (1902–1971) and witchcraft. This was followed by an overview of terminology and the significance of the different parts of guts. Since cattle form important social factors, there are diverging terminologies of bovine anatomical classification in rural Zululand: different stomachs, gallbladders, black and white small intestines. Guts are an important part of health and power, therefore many elixirs are on the market. The quantity of bile is important and in southern Africa is even vital to bodily and cosmological wellbeing. Finally COUSINS presented several images from contemporary artists depicting the belly and intestinal metaphors on political or sexual power. (<https://comparative-guts.net/africa-i>)

A historical classification was followed by JANE DRAYCOTT (University of Glasgow). In her contribution “Etruscan and Roman Guts” she made a differentiation of anatomical representations in ancient Greece, where mainly the external body was visualised. This was explained by an emerging disgust for entrails, whereas the Etruscans and Romans had a more positive attitude towards them. Different objects showing the interior belly were presented made of terracotta, bronze and one fresco. An exceptional Etruscan bronze model of a life-sized sheep-liver was presented: the “Piacenza Liver” (first century BCE) used for hepatoscopy. A polyvisceral plaque from around 400 BCE showing the stomach and intestines in a more or less naturalistic way was also presented – although the trachea is represented as a snake. Since anatomical votives were placed in a religious context for healing it is interpreted as a reference to the snake of Asklepios. An example from late antiquity/Christianity, in the fourth century CE, is the fresco from the hypogeum of Via Dino Compagni depicting a scene which is suggested to be an anatomy lesson. (<https://comparative-guts.net/roman-etruscan-materials>)

Beginning with a historical introduction to the Vedic Period 1500–500 BCE (Mantras), the *śramaṇa* Tradition and development of Buddhist medicine, JASON BIRCH (SOAS University of London) focused in his presentation “Yoga and Ayurvedic Medicine in South Asia (Ayurvedic and Yogic Guts)” on the the most important early Ayurvedic Texts: *Carakasamhitā* (2nd CE), *Suśrutasamhitā* (recompiled in 6th CE), and the *Aṣṭāṅga-hṛdaya-samhitā*. This was followed by an overview of the most important medical depiction of the interior in the ayurvedic context and digestion in the *Bhāvaprakāśa*. A Nepalese drawing of a human anatomical figure from 1800, which illustrates, and labels internal and external body parts was probably influenced by Tibetan medical Thangkas. Another image which was discussed broadly: A Gujarati manuscript from ca. 1900 (?) with Sanskrit and Gujarati labels shows tantric ideas in relation to the physical body. The influence of Persian anatomical drawings in the tradition of *Tashrīh-i badan-i insān* by MANṢŪR IBN IL-LYĀS mentioned by IGNACIO SANCHES is noted. (<https://comparative-guts.net/area-india/>)

The transfer of medical knowledge and images was again the central question in the discussion of the Daoist text and image compilation *Neijing tu* by LI JIONG (*Chart of the Inner Landscape*, 1269) by VIVIENNE LO (UCL History) in her contribution about China. The visual focus is on bones, solid organs and hollow guts which are accompanied by animals, spirits and state bureaucrats. When they travelled and arrived in different medical cultures they were selectively adopted and adapted in respective contexts outside China. VIVIENNE LO raised the question of whether we should talk about “Transcultural Guts” instead of “Comparative Guts” in this regard and asked what travelled and why? Why did some images or distinctive elements travel and others not? Several image details in the *Chart of the Inner Landscape* and its journey were analysed. For example, the images of RASHĪD AL-DĪN which arrived in Persia via the Mongolian Empire do not show animal spirits while the Korean reinterpretation does (*ui'bang'rgyuchui/Classified Collection of medical remedies*, 1477). (<https://comparative-guts.net/?s=Vivienne+Lo> sowie <https://comparative-guts.net/china>)

Friday, June 9

In their contribution “Contemporary Guts” BROOKE HOLMES (Princeton University) & MARTHA FRIEDMAN (contemporary Artist) took the view that there has been an increase in collaboration between artists and researchers over the past 25 years in contemporary art. An overview on contemporary art in the late twentieth and twenty first century contextualised the various pieces of art presented in time, space and transcultural movements. A vivid example of contemporary art in the medical humanities with scientific and societal reference was a dance choreography and installation on guts representing the microbiome by ISABEL LEWIS: *Scalable Skeletal Escalator* (2020), initially shown at Kunsthalle Zürich. The performance draws on symbiotic structures as stated by evolutionary biologist LYNN MARGULIS. A series of twelve works, the *Histology of the different Classes of Uterine Tumors* (2004–05) by WANGECHI MUTU refers to aspects of gender and “race”, while the performance *This is Offal* (2015) on the boundary between painting and poetry by MARY REID KELLY with PATRIC KELLEY (2015) broaches the issue

of silent female suicide. MARTHA FRIEDMAN'S work is a combination of ancient and contemporary art: *29 Untitled* (2018) is a series of 29 sculptures made of steel, glass and rubber, denoting the relationship between the gut and the cut and dealing experimentally with the material. (<https://comparative-guts.net/?s=brooke>)

JANE DRAYCOTT already mentioned that in ancient Greek depictions, hardly any internal organs are presented. The only exception was the examination of the liver of sacrificial animals in order to determine if the omens were good. However, in regards to humans, the only visualised internal material is blood. ROBIN OSBORNE (University of Cambridge) pointed out in his contribution “Greco-Roman Antiquity” that the Greeks cannot have been unaware of human innards. The avoidance of externalising the internal must have been for other reasons. There was enough knowledge from butchery practices and medical texts were full of descriptions of entrails. One example of texts gathered under the name of HIPPOKRATES is *On Anatomy*. (<https://comparative-guts.net/greco-roman-antiquity>)

CHANG CHE-CHIA (Institute of Modern History, Academia Sinica) presented in “China and Japan in the Modern Period” an image of a digital rendition of the organs of the Buddha made of silk to demonstrate that guts were important in the context of religious transmission. It was common to enshrine models of viscera in statues of the Buddha. It is the earliest surviving viscera model in East Asia and was made by a group of nuns and brought to Japan from Taizhou, Zhejiang in 985 (Seiryōji Monastery, Kyoto). For the exhibition the rendition was made by STELLA THUMIGER. Similar models are known in China, in some cases the stomach is filled with grains or the intestines with incense. There is also a 15th century pictorial scroll of Hippiastry held in Azabu University Library in Tokyo where organs are painted in 5 colours according to 5 elements.

A very special role is played by the so-called Manchu Anatomy, which the Jesuits hoped would help convert the Kangxi Emperor to Catholicism. The included images are copies of European anatomical paintings, but the external phenotype was often adopted to the Manchu appearance. CHANG CHE-CHIA presented many more examples and also referred to metaphorical terminology relat-

ing to guts. (<https://comparative-guts.net/china-and-japan-in-the-modern-period>)

CHRISTOPH GEIGER who designed the website and the printed edition of *Comparative Guts* explained his approach and process when designing the visual output of the project („The Digital Exhibition Comparative Guts: Interpretation, Translation, Design“). In his view design – a discipline between head and guts – is a box, or sophisticated container and has much to do with translation, knowledge transfer, and the psychology of graphic information. To translate content into visual explanation, design should sustain the reader’s attention by providing a good user experience. The Comparative Guts website presents images, so that they appear to come out of the dark, exploring the inside of the body through time and space. The design process is based on the project’s goal, content and budget. (www.christophgeiger.com)

The starting point of NATALIE KÖHLES (School of History and Philosophy of Science, University of Sydney) presentation, entitled “Anatomical Images in Northern Song China (960–1127)”, were drawings by the physician YANG JIE who, with the help of an accompanying artist, documented the dissection of the dead bodies of executed rebels. Even if the originals no longer exist, they still form the basis of the genre of *Cun zhen tu* (*Charts on Preserving the true [Essence]*) which is connected to the Daoist practice of bodily cultivation. The images depict more anatomical structures such as “tubes”, “mouths” and “gates” rather than physiological processes of “fluids”. The *Cun zhen tu* had a broad impact on most premodern representations of internal organs. Two of the oldest surviving copies were introduced and compared in detail: A Series of colourised Japanese images in the form of an Edo reprint (1603-1), based on KAJIWARA SHŌZEN’s medical work *Man’ampō* (*Myriad Relief Prescription*) written between 1315-25 and the Chinese work *Yi Yin Tangye Zhongjing Guang Wei dafa* (*yiji dafa; Yi Yin’s Decoction [Classic] Propagated as grand Methodology by [Zhang] Zhongjing*) composed by Wang Haogu. (<https://comparative-guts.net/anatomical-images-in-northern-song-china/>)

YI-LI WU (University of Michigan) highlighted in her presentation “Ming-Qing illustrations of the organs 1500–1850” contemporary and historical debates on images of the body in Chinese Medicine and started her presentation by refer-

ring to VOLKER SCHEID’s publication *Yun Tiegiao and the disappearance of the body* (2020) and cited YUN TIEQIAO: “The five organs of the inner Canon are not the five organs of flesh and blood but the five organs of the four seasonal (transformations).” She discussed the problematic separation of physical layout and circular function. In the *Diagram of the Inner Landscape in Illustrated Wind of the Classified Canon* (*Leijing tuyi* by ZHANG JIEBIN 1563–1640) a famous blockprint showing, visceral positions and connections in lateral view. Already at that time, the historical scholar ZHANG JIEBIN discussed that the “Gate of life” (mingmen) is not the right kidney but the Uterus, or “child palace” (*zigong*). She also refers to a diagram of the heart from WANG QI (16th cent) and debates on the number of channels, as well as observations of the corpse made by WANG QINGREN (1830) to demonstrate that the legend that Chinese medicine is not interested in anatomy is not true. (<https://comparative-guts.net/ming-qing-illustrations-of-the-organs/>)

RODO PFISTER is a specialist in the composite text *Songs of the Bodily Husk*,³ by Master Yan Luo (10th cent CE) who is also known for lost Daoist texts in meditation and breathing practices. The work was printed in 1445/46 and in a later edition the images were redrawn. The *Treatise on the Inner Realm by Superintendent Zhu* includes critical comments on body maps. RODO PFISTER presented in his contribution “The Body Maps of Master Yan Luo, as Used in Meditation, Anatomically Corrected by Superintendent Zhu” corrections and different versions of the images and discourses on the differences and discrepancies between the inner scenery experienced in the context of inward observations during meditation and empirical findings during the dissection of dead bodies. In addition, the so called five storehouses or locations for five spiritual beings (Hun, Po, Zhi, Yi, and Shen) are used differently in the context of medicine and meditation. (<https://comparative-guts.net/the-body-maps-of-master-yan-luo>)

JAMES FLOWER (Kyung Hee University) apologised in his contribution “Images of the Digestive Organs in Korea” for not being able to present many images and raised the question why Koreans do not have colourful images compared with others. It could be that they were taken to Japan or disappeared, or that there are no images because

there was a common belief that to illustrate the inner body would miss the point. Socially anchored in Confucianism, many medical texts show aspects of Taoism and Buddhism including ideas of the emptiness of the body and its invisibility. The spleen is related to the earth element and the centrality of the organ is important. While in Chinese culture the heart is regarded as the “King of Organs”, the spleen became important in Korea because it processes food and drink. A lively discussion started with regards to what is meant by the organ “spleen”. While some argued that one should also talk about the function of the pancreas JAMES FLOWER stated that most Koreans talk about the microbiome when they talk about the spleen. Since he has found a painting where the spleen also resembles a horseshoe, the duodenum is also taken into consideration to be part of the system named spleen. (<https://comparative-guts.net/images-of-the-digestive-organs-in-korea/>)

During one of our preparatory online meetings HISA KURIYAMA suggested that it would be wonderful if the project could include contributions for visually impaired people. CHIARA THUMIGER started a sub-project “The felt body: a multisensory approach: For and with a visually-impaired public” with the help of art historians ALMUT RIX and MICHAELA WILK, where additional effort was made to be inclusive for people without visual access. Image descriptions were prepared for around 50 images. During the workshop SILJA KORN, a visually impaired photographer and artist from Berlin, presented her “Lightpainting Art.” Four tactile plates were demonstrated based on images of the Comparative Guts exhibition. In the meantime, ten tactile books with ten plates were created. The workshop was generously supported by the CAU Inclusion Fund. The second part of the workshop was dedicated to the olfactory sense.

VICTOR GRUBOV & SEAN COUGHLIN (Czech, Academy of Sciences, Prag) pointed out in their contribution “Scent of Ancient Guts” that the reconstruction of the smell of the Antique, the alchemy of scent is a challenge. On an antique vase with sceneries of butchery and a detailed description of the process are depicted. The stages of slaughter, the removal or roasting of entrails have different smells, depending on what the animals have eaten or (in modern times) if they were treated with antibiotics. To get an idea of such at-

mosphere KLARA RAVAT (scent artist and designer) created sent samples which made the smell of the stages of antique slaughter experienceable in an experimental olfactory workshop, ending with a sensual conclusion of the comparative guts conference.

References

- 1 See THUMIGER, CHIARA (ed) 2024. *Comperative Guts: Exploring the Inside of the Body through time and space*. Kiel: Christian Albrecht University zu Kiel, Cluster of Excellence Roots (https://macau.uni-kiel.de/receive/macau_mods_00004630?lang=en).
- 2 BOLSOKHOEVA, NATALIA 2016. Tibetan Medical Illustrations from Atsagat MedicalCollege and other Anatomical Achievements of the Buryat Lama and Physician D. Endonov. *Curare* 39, 1: 6–21.
- 3 PFISTER, RODO 2016. On the Meditative Use of the Body Maps Found in the composite Text “Songs of the Bodily Husk” (Ti ke ge). *Curare* 39, 1: 56–74.



Katharina Sabernig is project leader of the FWF project “Knitted Body Materiality” (doi: 10.55776/AR705) at the University of Applied Arts Vienna and studied medicine and cultural anthropology in Vienna. In her previous projects she focused on anatomical illustrations, visualized medicine and Tibetan medical terminology, about which she has published extensively. Inspired by the diversity of anatomical representations and the ethical issues involved, she began knitting anatomical objects in 2015 to find answers to various questions regarding ethics, materiality and perception of anatomical presentation. In her current project, the three-dimensional textile creations are not only exhibited, but also presented through photography, video animation and performative anatomical theater.

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REZENSIONEN
BOOK REVIEWS

BOOK REVIEWS



KRISTEN SMITH 2022. *Medical Tourism and Inequity in India. The Hyper-Commodification of Healthcare.*

Lanham: Lexington. 208 pp. (17 figures)

KRISTEN SMITH is a senior research fellow at the University of Melbourne, Australia, where she focuses on medical anthropology, health equity, globalization, political economy, development, mobility, and Indigenous studies. Her Ph.D. thesis on medical tourism and health inequity is the result of multi-sited hospital ethnographic fieldwork in the greater Mumbai area between 2009 and 2010. It has been published in the book series “The Anthropology of Tourism: Heritage, Mobility, and Society” (edited by MICHAEL A. DI GIOVINE).

With the example of India, the author draws our attention to the intensive privatization and commodification of healthcare across the globe and related tensions, conflicts, and contradictions. She describes medical tourism as an economic strategy for developing and emerging nations and, at the same time, a provisional remedy for patients facing costs, long waiting periods, or lack of access to medical specialists at home. Her research questions touch upon the implications of this growing industry for health workers, patients, local healthcare structures, and related economies. Further, she also mentions their fragility in the context of the COVID-19 pandemic, even though it remains unclear how far she was able to anthropologically study it over a decade later. She addresses the decrease of charitable public health resources, particularly for the lower social classes, in the context of market-led health policy and explores emerging life-worlds within globalizing biomedical institutions framed by economic patterns of neoliberalism. In this, she does not take the health tourists’ perspectives but those of the hosts, such as institutions, workforce, local population, and transformations within broader social,

political, and economic processes and structures. Again, she also refers to developments after her field research such as under India’s Prime Minister Narendra Modi (since 2014). Her account becomes an illustration of inequalities in India (and the world) between privileged “haves” and brutally dehumanized “have nots” and, therefore, an essential contribution to Critical Medical Anthropology. On the other hand, the author also explores aesthetic aspects in describing hotel-like clinics with their fresh and calm atmosphere in opposition to the hot, damp, dusty outside, with facilities such as shopping malls, residential houses, cinemas, restaurants, and a general city-planning that with its cosmopolitan lifestyle differs so much from “general” Mumbai’s urban reality and sick-making slums.

Apart from her introduction and conclusion, KRISTEN SMITH introduces us to this environment in six interrelated chapters. Chapter 1 (First World Treatment at Third World Prices) locates medical tourism in capitalist circuits of production and consumption, engaging with issues of agency, power, equity, and development processes. Chapter 2 (Medical Tourism and the Hyper-commodification of Healthcare) explores India’s 20th-century healthcare shifts away from Indigenous therapies toward biomedicine and hyper-commodification, which left a vast majority of the population excluded from health resources. Chapter 3 (The Intersections of Tourism and Health: The Marketization of Medical Tourism) then turns to different actors engaging in medical tourism, from local hospitals to international travel agencies to global stakeholders such as multilateral institutions and multinational cor-

porations. It addresses national efforts and those of private hospitals in Mumbai, tapping into a nascent medical tourism supply chain attaching itself to broader tourism supply chains including their “affective branding” and digital marketing. It is here that some pull-triggers for the actual patients also become visible.

Chapter 4 (Places in Peril: Medical Tourism and the Transitioning of Trust), however, draws our attention back to local disruptions in the delivery of healthcare services to the resident population, particularly at initially charitable so-called Trust hospitals that, due to their precarious economic situation are forced to compete with private clinics without any transparent state funding and control policy. Hospitals, originally belonging to a not-for-profit sector, become sites of investment and structural violence against citizens. Chapter 5 (Mobility, Identity, and the Global Imaginary: The Worlding of Healthcare Workforce) illustrates the impacts on health workers trapped between exploitation and career, medical ethos, and corruption in a medical system where tourists may become cash cows and stirrup holders. Chapter 6 (The Structural Violence of Medical Tourism: Gated Enclaves and Health Exclusion) summarizes the negative aspects of observed medical tourism practices:

Medical tourism is aligned with increasing flows of geographic and economic mobility for some and is directly connected to the immobility of others. It supports and reinforces barriers to a wide range of goods and services for local host populations, contributing to the deterioration of health equity in the nation. (137)

Of course, health inequity links to broader inequalities such as economic, geographic, or social stratification, but, as KRISTEN SMITH clearly points out, medical tourism is not just an effect of but also causes increasing healthcare inequalities in microcosms of social exclusion and exclusivity. Like in CALDEIRA's (2000) reflection on São Paulo/Brazil as the “City of Walls,” she detects barriers to protect the rich and keep out the poor. The devastating effect of ongoing privatization and commodification of the healthcare sector is, according to her, that medical tourism does bring more money but also raises prices. In her conclusion, she, therefore, correctly asks:

[...] will the ‘world class’ technocratic quality improvements underway in the elite private hospitals in developing contexts such as India translate to long-term changes that will eventually permeate the entire healthcare sector? If so, at what cost? (161)

As a reviewer, I have not much to add besides my gratitude for such a clear-cut analysis of contemporary frightening developments in global healthcare and that we have to further observe these developments. However, we should also be aware of other forms of medical tourism the author mentions but does not further explore. There are examples of medical tourism serving to escape the grip of capitalist biomedicine, and it would be interesting to see if they could not be a way to strengthen local health practices.

HELMAR KURZ, Münster

Reference

CALDEIRA, TERESA P.R. 2002. *City of Walls. Crime Segregation, and Citizenship in São Paulo*. University of California Press.

ANGEL MARTÍNEZ-HERNÁEZ & LINA MASANA (eds) 2022. Subjectivities and Afflictions in Medical Anthropology.

Cambridge: Cambridge Scholars Publishing. 291 pp. (2 Figures)

Over 30 years after ARTHUR KLEINMAN's (1988) seminal work on illness narratives, subjectivities still receive little attention in Western biomedicine. The editors of this volume argue that

[d]espite some recent changes aiming at humanizing medical care by taking a more person-centered approach [...], biomedical representations and practices continue to focus mainly on diseases rather than on the patient's illness experience (1).

They understand subjectivity as the intersection of the experiencing/experienced body with micro- and macro-level contexts (local social worlds, power relations, conflicts between lay knowledge and expert systems, etc.). Accordingly, as the result of the X Medical Anthropology at Home (MAAH) Conference held at Poblet Monastery (Tarragona) in October 2018, the authors of the 14 chapters explore spaces of subjectivity in routines of cure and care and the possibility of medical anthropology providing alternative approaches "focusing on a politics for life instead of a politics of biological life that detaches subjectivity from health policies and practices" (1). The chapters are organized into four sections, investigating suffering as an expression of the human condition and its relatedness to social worlds with its healthcare systems.

Section I (Negotiating Knowledge and Subjectivities: Illness Narratives and the Biomedical and Social Construction of Disease) addresses the following questions:

Is subjectivity changed, shaped, or negotiated in [...] different narrative encounters? Are the subjective worlds of affliction mere accounts of symptoms and ailments, or do they serve other purposes? How is [sic] illness expertise and experiential knowledge negotiated in the biomedical and social arena? To what extent does the social construction of the disease come from the original illness account or from an official discourse? (2f)

Three chapters on chronic conditions (cancer, chronic fatigue, AIDS) attempt to respond to these questions, partially integrating autoethnograph-

ic accounts. In chapter 1, SUSAN M. DIGIACOMO (Healing and Wholeness: Cancer Survivors' Embodied Experience of Illness as a Source of Expertise) reports her experience as a volunteer in the US-American Patient Network where "survivors" of a cancer diagnosis guide newly diagnosed patients through the ongoing transformations of body- and self-experiences. They develop "expertise" different from the biomedical one but crucial to negotiating states of ongoing liminality and the "sudden shift from one mode of being to another" (15). Participants become "acutely aware of their bodies" (15) beyond mere coping and develop a form of re-embodiment understood as new somatic modes of attention and ways "how to live" (16). In this regard, the author also criticizes "immunological metaphors that predispose us to think in terms of war, victory and defeat [because] getting the status quo ante back after cancer is all but impossible" (18). She suggests asking "[w]hat have you learned from having cancer?" (19)

Another example of the need for new modes of awareness is introduced in chapter 2 by LINA MASANA ("We Are All Tired": The Social Construction and Negotiation of Chronic Fatigue). Presenting a Spanish case study of a woman suffering from chronic fatigue and certain incidents during a hiking trip, she illustrates how social responses may relativize, delegitimize, and contest ill-body experiences due to a lack of empathy even of very close fellows and relatives. Whereas the previous chapter has affected me because the author passed away during the publication process (a piece of information shared by the editors) and I personally mourn for good friends who in similar circumstances would have profited a lot from such an approach, this second chapter makes me (as a passionate hiker) aware of my ignorance of and impatience with the needs of others. The author stresses the factor of (ill) communication, but to me, her study also illustrates the interdependence of the categories of illness (personal experience), disease (medical diagnosis), and sickness (social implications) and how the latter may affect the former. We currently observe similar challenges

with the affliction of Long Covid, as we did in the past with HIV/AIDS.

WESAM ADEL HASSAN, in chapter 3 (*Navigating HIV Discursive Practices and Positive Subjectivities in Egypt*), draws our attention to the latter context with the particular ethnographic example of Egypt and the social and medical exclusion HIV “positive” patients suffer from. The author focuses on a particular group of mothers living with HIV, some of them also helping newly diagnosed patients (compare chapter 1). Her main interest is in how they enact “their agency and their will to live through their maternal subjectivity, and their impressive daily negotiation of the dominant political, medical, and social surroundings” (45). She touches upon religious and moral convictions and related stigma driven by fear and ignorance policies, the categorization of patients, and strategies of othering / blaming others in social interaction and media productions (a strategy also well-known from the COVID-19 pandemic). A case study illustrates the struggles, hopes, and fears in everyday life, particularly regarding the social role of a mother and caretaker for their sometimes also “positive” and, differently, for their healthy children.

Section II (*Hospital Ethnographies and Subjectivities: Encounters between Health Professionals, Patients, Families, Clowns, and Ethnographers*) inquires in three chapters about the interplay between the professional and lay subjectivities but also wondering

[h]ow does ethnographic research affect anthropologists? How do the anthropologist’s subjectivity and presence in the health setting affect research and clinical encounters? How do researchers deal with emotions encountered in the field? (4)

In chapter 4, CLAIRE BODELET (*Re-Experiencing Medical Care Routines Through the Work of Hospital Clowns*) observes the interaction of hospital clowns with the medical staff, family members, and patients in a French pediatric clinic, where “humour is not always the appropriate solution” (65). The author explores their subjectivities and specific situations where clowns either support the work of medical staff or the “patient’s work”. In the former case, medical staff members might call them to distract patients from medical interven-

tions; in the latter, they may initiate coping strategies and individual support for the child’s control of emotions such as fear and sadness. Accordingly, “clowns must learn the technical work, but they also must learn how to manage an unstable environment in which they must have the appropriate gestures” (66), linking “their performance to an exploration and understanding of their environment” (67). However, by presenting a case study, the author also reflects on the positionalities and subjectivities of researchers in hospital ethnographies and how their work may transform them. In her case, the clowns helped her by integrating her into their performances but also by transforming her perspectives on her research topic.

In chapter 5, SYLVIE FORTIN & JOSIANE LE GALL (*Prolonging Life or Envisioning Death*) direct our attention to another emotionally challenging context of pediatric care. It “was inspired by an encounter with a young man, at the end of his life” (81) and decision-making processes among the medical staff and his parents. The decision in question is when to stop with curative and begin with palliative treatments. The contribution thus (in the reviewer’s opinion) questions the contemporary biomedical practice of “furthering life at all costs” (82). The setting is a Canadian clinic for pediatric hematopoietic transplants where “different subjectivities are played out, modulating clinical practice, therapeutic relationships and finally, end of life care” (83). The authors describe decision-making spans “from a paternalistic perspective where the physician plays a leading role to an autonomist model, where the patient and their parents [...] take a leading part in care decisions” (84). They introduce the model of a partnership that promotes new configurations of therapeutic relationships in which patients and families develop expertise. However, in the context of the case study, it appears that families’ decisions either contradict medical expertise or put their hope in ever-new technologies and unnecessarily extend suffering. It is not necessarily the authors’ opinion but the reviewer’s impression.

Chapter 6 takes SABRINA LESSARD (*If I Understand Correctly, You’re Waiting for One of Us to Die?*) to another context regarding end-of-life discussions and deserves my full respect for publicly addressing the ongoing problem of what I would like to call the obligation to live. It also relates to

the Canadian context but addresses “the issue of dying with dignity” in elderly care. It further reflects the researcher’s ambiguous positionality in the field, located between personal empathy, the feeling of being voyeuristic, and the need for data collection: “The scenes I witnessed reminded me to overcome the urge to flee the suffering of others or turn them into spectacle” (101). The author shares her disorientation in the field, dealing with end-of-life situations, death, and the social and medical implications of “deliberating on extending life or choosing death” (104), particularly when patients are prevented from dying:

Their deaths were stretched out over time. The medical care they received was so effective that they could only die if their bodies didn’t respond to treatment [or] [...] if they said a final no to this culture of ‘you shall not die’. [...] I belong to a society where it is wrong to die (105).

Again, I feel myself reminded of COVID-19-related health policies where basic human rights have been dismissed for the sake of the government of life.

Section III (Negotiating Subjectivities: Body, Substances, Biopolitics and Health Practices), with three chapters on human-substance relationships, addresses this government-of-life aspect in the management of human affliction. However, even more important for the discussion throughout this edited volume is the question: “Is there a place for agency in the biopolitics framework” (6)?

In chapter 7, SYLVIE FAINZANG (Subjectivities and Semantic Variations Around the Concept of Dependence on Medicines) investigates the lay management of medicinal risks with the example of French patients’ fears of dependence on substances. The author reflects on their subjectivities at the intersection of two oppositions: “one between the subjective and the collective and the other between subjectivity and objectivity” (115). According to her, “discussing subjectivity does not necessarily involve taking an interest in the perceptions/representations/emotions/sensations of an individual. And [sic] therefore, does not necessarily involve only taking an interest in ‘subjective feelings’ [...], but also focusing on the subjective *constructions* of a phenomenon, that are simultaneously bodily, social and existential. Yet

these constructions are not exclusively individual” (116f).

She illustrates divergent discourses beyond the concept of bodily/mental addiction among “objective” medical professionals and “subjective” patients and strategies relating to social constructions of self-control and emancipation. Further, she observes an increasing fear of dependence in France in the last two decades. She relates it to an increasing impact “of Anglo-Saxon models of autonomy and the responsabilisation of the patient” (123).

In chapter 8, NICOLÁS MORALES (Pharmakon, Commodity and Dystopia: Three Approaches to the Pharmaceutical Self in Neo-Communitarian Mental Health) in a more historical and philosophical approach, continues to discuss the relations of patients to pharmaceuticals in the Chilean mental healthcare context. His account navigates from the “most ardent defenders as a panacea for the brain’s chemical imbalance [...] to those who denounce what has become ‘a sedated society’ [...] [and] a fragile balance between the healthy and the mortal” (132). The author explores “the use of psychiatric medications in commodified clinical practice through the commodity fetishism metaphor” (132) and “pharmaceutical imaginaries” in the form of the “pharmaceutical self” and dystopic narratives of large-scale sedation. The chapter contributes to the investigation of the history and critical practices throughout the Chilean dictatorship (including the German Nazi Colonia Dignidad), and more broadly, of psychiatry and community mental healthcare services.

With chapter 9, FRANZ GRAF (Ecological Subjectivity: A Case of Chemical and Other More-Than-Human Sensitivities) returns to anthropological research based on case studies and, at the same time, broadens our perspectives on human relations to chemical substances and other materialities. The author introduces the case of a woman in Britain who has developed a hyper-sensitivity to all kinds of artificial chemical substances (multiple chemical sensitivity) impacting her in an urban modern context and who seeks relief in natural environments and British Paganism. Instead of understanding her individual transformation as a symbolic representation in terms of denying the malcontents of modernity or an alleged nature-culture-antagonism, he focuses on

the emotional and sensory aspects of her experiences. Integrating the theoretical concept of embodiment, he argues that affliction highlights “a specific bodily relationship to the world” (159) and wonders about “the question of agency in the body-world relationships” (159).

Section IV (Mental Health Narratives, Embodiment, Healing Practices and Subjectivities) further investigates these aspects in five chapters, highlighting how illness is not merely the result of a biological imbalance affecting the body or the mind but a subjective experience affecting the life-world. It investigates how subjectivities are perceived socially, medically, religiously, and spiritually and how they may

counter the biomedical paradigm, and function as a corrective to biomedical reductionism and the hegemonic normative ideas on how bodies and minds are, or should be, expressed, socially (re) presented, understood, treated or healed (7).

It further addresses the intersection, and sometimes opposition, of sensory and cognitive aspects of healing, cure, and care.

In chapter 10, SOULA MARINOUDI (Uncharted Sensations: Autistic Subjectivities, Affective Language and Unexpected Senses) outlines related dissonances based on case studies on Autism, or to be more correct, on the interaction of so-called “neurotypicals” with “autistically” classified persons in Greece. Overall, the author stresses the fact of divergent ways of perceiving and interacting with the environment, exemplarily discussing nuances of cognitive/linguistic vs. sensory/bodily interactions and the need for empathy, patience, and goodwill to negotiate and intermediate between these spheres. This contribution, in the opinion of the reviewer, very much corresponds to an earlier issue of *Curare* (see Kurz 2019) on the Aesthetics of Healing but takes a further step: it not only refers to different ways of being in the world but to contexts and processes of mutual understanding and learning of each other, of stepping back from own subjectivities and providing space for the others'. Bridging and integrating experienced life-worlds might not only provide more agency to (alleged) patients but, overall, free them from a disease category and acknowledge divergent self-other orientations.

With chapter 11, ANGEL MARTÍNEZ-HERNÁEZ (The Son of the Tiger Hunter Who Never Killed a Tiger: Myth, Violence and Masculinity in a Life Story) takes a different stance than on an experiential and cognitive level connects individual biographical narratives with provided patterns of myth in a transcultural context. Introducing the case study of a person of Indian descent in a mental healthcare institution in Spain, the author develops a quite symbolical and philosophical argument on the patient's experience that appears to resemble various Hinduistic, Christian, and even psychoanalytical myths and interpretations, transgressing these boundaries and giving space to individual subjectivities using social/public and mythical/religious representations as a sketch or draft to locate one's own affliction.

In chapter 12, PATRICIA COCCHI, ISMAEL APUD, JUAN SCURO & ADRIANA MOLAS (Narratives of Violence and Alterity of a Psychonautic Woman) discuss the case of a woman in Uruguay who suffered abuse and mistreatment in both a neo-shamanic spiritual community and a psychiatric clinic. The authors explore her biography starting with her “quest for new emancipatory models against Western materialistic modern life” (219), illustrating experiential and subjective processes of alterity at the intersection of medical anthropology and religious studies. They describe trajectories “related to different health, religious, artistic, and educational contexts, with their own social dynamics and cultural backgrounds” (220). They “analyse how these trajectories impacted her subjectivity, and how the process of subjectivation was not passive, but active and creative” (220). A very interesting aspect is the comparison of sanctioning non-conformity in neo-shamanic groups with their use of psychedelic substances and biomedical psychiatry. In the end, only emancipation from both and following her subjective needs has provided sustained relief.

In chapter 13, DANUTA PENKALA-GAWĘCKA (Illness Experience and Its Translation: The Case of a 'Shamanic/Healer's Illness' in Post-Soviet Kazakhstan and Kyrgyzstan) continues to explore the relationship between shamanism, spirituality, and mental healthcare but on the complementary level of healing cooperation in former Soviet republics. The author focuses on the experience of “ini-

tiation illness”, a recurrent concept in studies on shamanism and other spiritual-religious healing practices, but in a different alignment. She illustrates that different from historical accounts, “[s]uch encounters and revelations often happened after unsuccessful biomedical [and/or psychiatric] treatment” (245). Accordingly, the author investigates how experiences are “translated” from one healing profession to the other, stressing subjective and intersubjective (and intercorporeal) aspects. In particular, she focuses on “the role of experienced healers, mediators between spirits and individuals chosen to become healers, in the process of translation of ‘mental illness’ into the ‘call of spirits’” (247). However, it raises the problem that in contemporary contexts, “the asymmetries in the shaman’s (or another spiritual healer’s) and the patient’s knowledge are much greater” (249) than with biomedical and psychiatric health professionals.

Corresponding to the fact that many authors in this edited volume refer to the concept of embodiment, the final chapter 14 gives the word to THOMAS CSORDAS (*Possession and Psychopathology, Faith and Reason*), even though his contribution refers more to the relation of medicine and religion and the subjectivities of respective therapeutic experts. The author refers to exorcism in the Roman Catholic Church and how exorcists and biomedical / psychiatric professionals of the Catholic denomination cooperate. After providing a historical account of exorcist practices and their regulation by the Vatican, he focuses on the subjective narratives of a Spanish psychiatrist engaging with exorcist explanatory models and practices in cooperation with two priests. He shares three case study vignettes: “The first is a case he ascribed to mental illness, the second to demonic possession, and the third at the time of his narration was still ambiguous and as yet to be determined” (273). The reading of these accounts produces very critical feelings in the reviewer because of the revealed inconsistencies and, from a medical perspective, misjudgments.

In line with the declared orientation of this volume, I, as the reviewer, can only present a subjective evaluation of the several chapters and the overall composition. Some contributions harmonize with my medical anthropological perspectives whereas others do not but still present rich

data to be further analyzed. I want to stress that I enjoyed reading every single contribution of this volume that, in its entirety, negotiates and integrates divergent perspectives on the subjectivity of affliction in medical anthropology and, in its majority, focuses on the agency of patients (apologizes for the oxymoron). The reviewer regards this volume as a delightful and necessary reading for medical anthropologists and therapeutic professionals to overcome their long-standing ignorance toward individual and social aesthetic experiences and evaluations in biomedical/psychiatric health-care, postulating a more empathetic integration of divergent experiences, interpretations, and solutions to human suffering and to-other-than-human relations. It is an essential contribution to the medical anthropology of emotional, sensory, and aesthetic aspects of cure and care. Particularly medical students and health professionals will gain a lot from this impressive composition of divergent accounts of (inter)subjectivities and experiences of affliction in various settings and environments. I further recommend the volume as a textbook in courses of (medical) anthropology, psychology, (transcultural) psychiatry, nursing training, and other health-related professions.

HELMAR KURZ, Münster

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ZUSAMMENFASSUNGEN
ABSTRACTS
RÉSUMÉS

Zusammenfassungen der Beiträge der *Curare* 46 (2023) 1

Visuelle Ausdrucksformen von Gesundheit, Krankheit und Heilung

HERAUSGEGEBEN VON KATHARINA SABERNIG

BARBARA GERKE: Visuelle Dynamik der Ansteckung: Gifte und Gegengifte in tibetischen medizinischen Gemälden des siebzehnten Jahrhunderts S. 13–27, verfasst auf Englisch

Wie lässt sich die Ausbreitung von Krankheiten visuell darstellen? Tibetische Künstler um die Wende des siebzehnten Jahrhunderts müssen sich genau diese Frage gestellt haben, als sie eine Reihe medizinischer Rollbilder anfertigten, von denen eines hier diskutiert wird. Sie wurden gemalt, um die medizinischen Schriften des Regenten des Fünften Dalai Lama, Desi Sangyé Gyatso, zu illustrieren, insbesondere seinen Kommentar zu den Vier Tantras, einer wichtigen medizinischen Abhandlung aus dem zwölften Jahrhundert. Sangyé Gyatso beauftragte die Anfertigung dieser Rollbilder in Lhasa. Sie dienten pädagogischen, aber auch politischen Zwecken. Im Mittelpunkt dieser visuellen Erzählung steht die Darstellung eines indischen Ursprungsmythos über Gifte, der sich mit Elixieren auf der Suche nach Unsterblichkeit beschäftigt. Im Kontext umfassenderer Konzepte

der Krankheitsübertragung eröffnet das vorgestellte Gemälde eine Untersuchung über die Verflechtungen medizinischer Vorstellungen von Vergiftungen. Die Bilder enthüllen tibetische medizinische Konzepte von Potenz und verbinden das Giftige mit dem Medizinischen auf faszinierende Weise: Giftige Substanzen könnten bei richtiger Verarbeitung auch als Gegengift bei Vergiftungen eingesetzt werden, sie könnten aber auch verwendet werden, um eine absichtliche Vergiftung herbeizuführen. Anhand vorhandener Reproduktionen dieser Bilder untersucht und analysiert dieser Artikel die Dynamik zwischen Formen der Vergiftung und den zur Behandlung von Vergiftungen eingesetzten Gegenmitteln. Welches Verständnis von Vergiftung und Ansteckung können wir aus diesem fast vierhundert Jahre alten medizinischen Gemälde gewinnen?

Schlagwörter Tibetische Medizin (Sowa Rigpa) – Ansteckung – Vergiftung – Medizinische Ikonographie – Vier Tantras (*Rgyud bzhi*)

ELIZABETH TURK: „Kultiviert sein“, die Kultur verändern: Botschaften zur öffentlichen Gesundheit im Ulaanbaatar der COVID-Ära S. 29–45, verfasst auf Englisch

Die poetischen und politischen Bilder, die von öffentlichen Gesundheitskampagnen mobilisiert werden, sind oft dicht an Bedeutung und Assoziationen, auch wenn sie bestimmte Annahmen über das Gute, Tugendhafte, Natürliche und Richtige enthalten. Dieser Artikel untersucht die Annahmen über „kultiviert sein“, die der Kampagne „Lasst uns die Stadt kultiviert machen“ und den damit verbundenen Botschaften zur öffentlichen Gesundheit in Ulaanbaatar, der Hauptstadt der Mongolei, zugrunde liegen. In den Bild-Slogan-Komplexen, die durch solche Kampagnen mobilisiert werden, wird „kultiviert sein“ (*soyoltoi*), gesund (*erüül*) und sauber (*tsever*) mit der Eindämmung bestimmter Verhaltensweisen wie Urinieren und Spucken in der Öffentlichkeit in

Verbindung gebracht, die während der COVID-19-Pandemie in gesundheitsbezogenen Diskursen eine neue Dringlichkeit erhielten. Als ein Konzept, das das Erbe von Bedeutungen und Assoziationen im Zusammenhang mit den Werten der staatssozialistischen Ära bewahrt, wurde „kultiviert sein“ im 20. und 21. Jahrhundert auf unterschiedliche, aber miteinander verbundene Weise verwendet, um hegemoniale Botschaften zu verbreiten. Anhand der Kampagne „Let’s Make the City Cultured“ und ähnlicher ideologischer Kampagnen zur öffentlichen Gesundheit untersucht dieser Artikel die diskursiven Bemühungen, ein Staatssubjekt zu schaffen, das bürgerliche Werte vertritt.

Schlagwörter politische Ökonomie – ideologischer Staatsapparat – Exemplare – Postsozialismus – Propaganda

SASKIA JÜNGER & MARIYA LORKE: Visuelle Ausdrucksformen von verkörperten Risiko. Körperkarten als Mittel zur Reflexion und zum Verständnis der Bedeutung von Gesundheitsrisiken in Forschung und Lehre S. 47–67, verfasst auf Englisch

Mit den zunehmenden Möglichkeiten der Risikofrüherkennung in der Biomedizin hat die Kommunikation statistischer Wahrscheinlichkeiten von Erkrankungen an Bedeutung gewonnen. Risikokommunikation zielt auf die Förderung von Risikokompetenz, die als Voraussetzung für informierte Entscheidungen zur Risikominimierung gilt. Grafische Darstellungen spielen in diesem Zusammenhang eine entscheidende Rolle; unter anderem werden stilisierte menschliche Silhouetten verwendet, um Wahrscheinlichkeiten zu visualisieren, z. B. um anzuzeigen, wie viele von hundert Personen an einer Krankheit erkranken oder nicht erkranken werden. Dies mag zwar die Risikokompetenz im Sinne eines leichteren „Erfassens“ abstrakter Statistiken fördern; die individuelle Bedeutung der Risikowahrscheinlichkeit für den eigenen Lebenskontext zu begreifen, bleibt dennoch schwierig. Wie wäre es also, dieses Prinzip umzukehren und die stilisierte menschliche Silhouette stattdessen zu verwenden, um die individuelle und kollektive Bedeutung zu visualisieren, die einem bestimmten – realen oder

imaginären – Krankheitsrisiko zugeschrieben wird? Im Rahmen einer Studie zur Gesundheitskompetenz von Menschen mit erhöhtem Krankheitsrisiko haben wir Body Maps in Forschung und Lehre eingesetzt. Es wurden narrative Interviews mit 20 Personen durchgeführt, die über ein erhöhtes Risiko für familiären Brust- und Eierstockkrebs oder Psychose informiert worden waren. Gegen Ende jedes Interviews luden wir unsere Informant:innen, zu einer Body-Mapping Aufgabe ein und baten sie, mithilfe einer auf einem Blatt Papier stilisierten menschlichen Silhouette ihr Krankheitsrisiko aufzuzeichnen. In der Lehre baten wir Medizinstudierende im Rahmen eines Ethikseminars, anhand eines Fallbeispiels die Body-Mapping-Aufgabe in Kleingruppen auf einem Flipchart-Blatt umzusetzen. Ausgehend von unseren Erkenntnissen und Erfahrungen wird in diesem Beitrag das Potenzial von Body Maps als Mittel zur Reflexion und zum Verständnis von verkörperten Risiken in Forschung und Lehre diskutiert.

Schlagwörter Körperkarten – Gesundheitsrisiko – Risikoverständnis – Forschungsmethodik – Lehre

Article Abstracts of *Curare* 46 (2023) 1

Visual Expressions of Health, Illness and Healing

EDITED BY KATHARINA SABERNIG

BARBARA GERKE: Visual Metaphors of Contagion. Poisons and Antidotes in Tibetan Medical Paintings of the Seventeenth Century pp. 13–27, written in English

How does one visually depict the spread of disease? Tibetan artists at the turn of the seventeenth century must have asked themselves this very question when they prepared a series of medical scroll paintings, one of which will be discussed here. They were painted to illustrate the medical writings of the Fifth Dalai Lama's regent, DESI SANGYÉ GYATSO, specifically his commentary on the *Four Tantras*, an important medical treatise dating back to the twelfth century. SANGYÉ GYATSO oversaw the preparation of these scroll paintings in Lhasa. They were designed for educational but also political purposes.

At the heart of this visual narrative is the depiction of an Indic origin myth concerning poisons, exploring the themes of elixirs in the pursuit of immortality. The painting presented here steers an inquiry into the interconnectedness of medical ideas of poisoning within the broader notions of disease transmission. The images reveal Tibetan medical ideas of potency, interlinking the poisonous with the medicinal in intriguing ways: poisonous substances could also be used as antidotes to poisoning when properly processed, but they could also be “cast” to cause intentional poisoning. Through existing

reproductions of these visuals, this paper explores and analyzes the dynamics between forms of poisoning and the antidotes used to treat poisoning. What understand-

ing of poisoning and contagion can we draw from this almost four-hundred-year-old medical painting?

Keywords political economy – ideological state apparatus – exemplars – postsocialism – propaganda

ELIZABETH TURK: “Being Cultured”, Changing Culture. Public Health Messaging in Kovid-era Ulaanbaatar pp. 29–45, written in English

As poetic and political, images mobilized by public health campaigns are often dense with meaning and associations, even as they make certain assumptions about the good, virtuous, natural, and right. This article explores the assumptions about “being cultured” that underlie the “Let’s Make the City Cultured” campaign and related public health messaging in Ulaanbaatar, Mongolia’s capital city. In the image-slogan complexes mobilized by such campaigns, “being cultured” (soyoltoi), healthy (erүүл), and clean (tsever) is linked to curbing specific behaviors such as urinating and spitting in

public, which took on new urgency in health-related discourses during the COVID-19 pandemic. As a concept that retains the legacy of meanings and associations in connection with state socialist era values, “being cultured” has been used in different yet connected ways across the 20th and 21st centuries to disseminate hegemonic messages. Drawing on the “Let’s Make the City Cultured” and related ideological public health campaigns, this article explores discursive efforts to generate a subject of the state that espouses bourgeois values.

Keywords political economy – ideological state apparatus – exemplars – postsocialism – propaganda

SASKIA JÜNGER & MARIYA LORKE: Visual expressions of embodied risk. Body maps as a means of reflecting and understanding the meaning of health risk in research and teaching pp. 47–67, written in English

With increasing opportunities of early detection of risk in biomedicine, the communication of statistical likelihood of disease has gained importance. Risk communication is committed to the support of risk literacy, assumed to be a prerequisite for making informed decisions to minimise one’s risk. Graphical representations play a crucial role in this context; among others, stylised human silhouettes are employed to visualise likelihoods, for example to indicate the number of persons out of one hundred who will or will not get the disease. While this may support risk literacy in terms of more easily ‘grasping’ abstract statistics, still a risk likelihood is difficult to comprehend in terms of its meaning for one’s individual life. So what if this principle is inverted and the stylised human silhouette is used instead to visualise the individual and collective meaning

attributed to a certain – actual or envisioned – disease risk? In the context of a study on health literacy among persons with an increased disease risk, we employed body maps in research and in teaching. In the research project, we conducted narrative interviews with 20 persons who had been informed about having an increased risk for familial breast and ovarian cancer or psychosis. Towards the end of each interview, we invited our informants to do a body mapping exercise, using a stylised human silhouette on a sheet of paper and asking them to sketch their risk. In teaching, we invited medical students attending an ethics seminar to do a body mapping exercise in small groups based on a case example, using a stylised human silhouette on a flip chart sheet.

Keywords body maps – health risk – risk understanding – research methodology – teaching

Résumés des articles de Curare 46 (2023) 1

Expressions visuelles de la santé, de la maladie et de la guérison

SOUS LA DIRECTION DE KATHARINA SABERNIG

BARBARA GERKE: Dynamique visuelle de la contagion. Poisons et antidotes dans les peintures médicales tibétaines du XVII^e siècle p. 13–27, rédigé en anglais

Comment représenter visuellement la propagation d'une maladie ? Les artistes tibétains du début du XVII^e siècle ont dû se poser cette question lorsqu'ils ont préparé une série de peintures médicales sur rouleau, dont l'une sera abordée ici. Elles ont été peintes pour illustrer les écrits médicaux du régent du cinquième dalaï-lama, Desi Sangyé Gyatso, en particulier son commentaire sur les Quatre Tantras, un important traité médical datant du douzième siècle. Sangyé Gyatso a supervisé la préparation de ces peintures sur rouleau à Lhassa. Elles ont été conçues à des fins éducatives, mais aussi politiques. Au cœur de ce récit visuel se trouve la représentation d'un mythe d'origine indienne concernant les poisons, explorant les thèmes des élixirs dans la quête de l'immortalité. La peinture présentée ici mène une enquête

sur l'interconnexion des idées médicales d'empoisonnement avec les notions plus larges de transmission de maladies. Les images révèlent les idées médicales tibétaines sur la puissance, reliant le toxique au médicinal de manière intrigante : les substances toxiques peuvent également être utilisées comme antidotes à l'empoisonnement lorsqu'elles sont correctement traitées, mais elles peuvent aussi être «jetées» pour provoquer un empoisonnement intentionnel. À travers les reproductions existantes de ces images, cet article explore et analyse la dynamique entre les formes d'empoisonnement et les antidotes utilisés pour traiter l'empoisonnement. Quelle compréhension de l'empoisonnement et de la contagion pouvons-nous tirer de cette peinture médicale vieille de près de quatre cents ans ?

Mots-clés Médecine tibétaine (Sowa Rigpa) – contagion – empoisonnement – iconographie médicale – *Quatre Tantras* (Rgyud bzhi)

ELIZABETH TURK: «Être cultivé», changer la culture. Messages de santé publique dans l'Oulan-Bator de l'ère du COVID p. 29–45, rédigé en anglais

Les images poétiques et politiques mobilisées par les campagnes de santé publique sont souvent riches de sens et d'associations, même si elles contiennent certaines hypothèses sur ce qui est bon, vertueux, naturel et juste. Cet article examine les hypothèses sur «être cultivé» qui sous-tendent la campagne «Cultivons la ville» et les messages de santé publique qui y sont associés à Oulan-Bator, la capitale de la Mongolie. Dans les complexes image-slogan mobilisés par de telles campagnes, «être cultivé» (soyoltoi), sain (erüül) et propre (tsever) sont associés à l'endiguement de certains comportements comme uriner et cracher en public, qui ont acquis

une nouvelle urgence dans les discours liés à la santé lors de la pandémie de COVID-19. En tant que concept préservant l'héritage de significations et d'associations liées aux valeurs de l'ère socialiste d'État, «être cultivé» a été utilisé aux 20^e et 21^e siècles de différentes manières, mais liées entre elles, pour diffuser des messages hégémoniques. En s'appuyant sur la campagne «Let's Make the City Cultured» et sur des campagnes idéologiques similaires en matière de santé publique, cet article examine les efforts discursifs visant à créer un sujet d'État qui représente des valeurs bourgeoises.

Mots-clés économie politique – appareil d'État idéologique – exemples – postsocialisme – propagande

SASKIA JÜNGER & MARIYA LORKE: Expressions visuelles du risque incarné. Les cartes du corps comme moyen de réfléchir et de comprendre la signification du risque sanitaire dans la recherche et l'enseignement p. 47-67, rédigé en anglais

Avec l'augmentation des possibilités de détection précoce des risques en biomédecine, la communication de la probabilité statistique d'une maladie a gagné en importance. La communication sur les risques s'engage à soutenir la connaissance des risques, considérée comme une condition préalable à la prise de décisions éclairées pour minimiser les risques. Les représentations graphiques jouent un rôle crucial dans ce contexte; entre autres, des silhouettes humaines stylisées sont utilisées pour visualiser les probabilités, par exemple pour indiquer le nombre de personnes sur cent qui contracteront ou non la maladie. Bien que cela puisse contribuer à la maîtrise des risques en permettant de "saisir" plus facilement des statistiques abstraites, la probabilité d'un risque reste difficile à appréhender en termes de signification pour la vie individuelle.

Que se passe-t-il si ce principe est inversé et que la silhouette humaine stylisée est utilisée à la place pour visualiser la signification individuelle et collective attribuée à un certain risque de maladie – réel ou envisagé ? Dans le cadre d'une étude sur la littératie en matière de santé chez les personnes présentant un risque accru de mala-

die, nous avons utilisé des schémas corporels dans la recherche et dans l'enseignement. Dans le cadre du projet de recherche, nous avons mené des entretiens narratifs avec 20 personnes qui avaient été informées d'un risque accru de cancer familial du sein et de l'ovaire ou de psychose. Vers la fin de chaque entretien, nous avons invité nos informateurs à faire un exercice de cartographie corporelle, en utilisant une silhouette humaine stylisée sur une feuille de papier et en leur demandant d'esquisser leur risque. Dans le cadre de l'enseignement, nous avons invité les étudiants en médecine participant à un séminaire sur l'éthique à faire un exercice de cartographie corporelle en petits groupes sur la base d'un exemple de cas, en utilisant une silhouette humaine stylisée sur une feuille du tableau de conférence. S'appuyant sur nos résultats et nos expériences, cette contribution vise à discuter du potentiel des cartes corporelles en tant que moyen de réflexion et de compréhension du risque incarné dans la recherche et l'enseignement.

Mots-clés artes du corps – risques pour la santé – compréhension des risques – méthodologie de recherche – enseignement

Platz für visuelle Ausdrucksformen

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