



### **Biosociality of Cancer: Cultural Scripts and Cultural Universals**

**Mathews, Holly F., Nancy J. Burke, Eirini Kampriani (eds.). 2015. *Anthropologies of Cancer in Transnational Worlds*. New York, London: Routledge. xii + 269 pp. Hb.: \$145.00. ISBN: 9781138776937.**

**Clemente, Ignasi. 2015. *Uncertain Futures: Communication and Culture in Childhood Cancer Treatment*. Malden, Oxford: Wiley-Blackwell. 248 pp. Hb.: \$99.95. ISBN: 1118909712.**

*Anthropologies* and *Uncertain Futures* explore the same subject – the experience of cancer in a specific cultural context – yet, they are based on different approaches to cancer. First, Mathews and her colleagues explore cancer in adults, and Clemente focuses on childhood cancer. Second, Mathews and her colleagues conducted ethnographic studies within the field of medical and health anthropology; Clemente, as a linguistic anthropologist, observed children with cancer, their parents, and medical staff, as agents of communication and social interaction, using participant observation, interviews and conversation analysis. Finally, most of the twelve chapters of *Anthropologies* are focused on cancer-affected subjects (both patients and caregivers) in developing countries or immigrants living in developed countries. Field work was conducted in different locations and communities, including China, France, Brazil, India, Kenya and Puerto Rico, France, Scotland and Argentina, and the USA (Mexican and Filipino immigrants). Clemente's monographic study deals with the micro-context of a paediatric cancer unit in Catalonia, Spain. The above differences make these two volumes complementary, providing a broad perspective on the anthropology of cancer.

### **Cultural scripts**

The Foreword to *Anthropologies* begins with a critical comment on a famous best-seller *The Emperor of All Maladies: A Biography of Cancer*. The Mukherjee's book is described as 'limited because it is based solely on a "Western journey" rather than one stretching to all the corners of the world' (Mathews et al. 2015: x). The authors of *Anthropologies* set out to write 'an alternative biography of cancer', because: 'Cancer has a multifaceted history and needs anthropological and ethnographic representations that offer alternative conceptualizations to biomedicine's universalizing and hegemonic tendencies' (pp. x; 8).

Focusing on trans-cultural aspects of cancer is supported by recent developments in cancer epidemiology. Globally, the incidence of cancer was 14.1 million in 2012, and it is expected to rise to 25 million in the next two decades (World Health Organization 2014). Cancer is now a relevant medical and social issue in developing countries. Two-thirds of cancer patients live in developing countries (p. 156). The Western biomedical model of cancer has a strong international influence at a time when 'cancer has become a global epidemic' (p. 1). We are witnessing a transmission of dominant medical and social cancer models into the geographically, socially or politically marginal cancer cultures.

*Anthropologies* questions this dominant Western medical cancer discourse by exploring inter-cultural differences. In most chapters, two opposing scripts are distinguishable. According to the "Western script", patients diagnosed with cancer are sup-

posed to make a radical change in their lifestyle, habits, social life, pursuing personal growth, ‘toward a view of cancer as beneficial trauma because it paves the way for those who experience suffering to undergo a positive transformation and become better selves’ (Bell, cf. Mathews et al. 2015: 177). In contrast, patients in developing countries see cancer as an additional disruption to their already hard living conditions, and they insist on going back to their life routine and identities of mothers, care-givers, and housewives, even before it is recommended or feasible. The Western script is patient-centred, while the non-Western script is family-centred. The Western script focuses on a total self-overhaul, while the non-Western script demands the preservation of the old self. In Aureliano’s chapter about breast cancer patients in Brazil, it is clear that

... conventional medicine’s logic of self-care goes against working class women’s logic of caring for others, which, far from being perceived as a form of subordination, is rather a means of normalization of everyday life and a demonstration of autonomy and health (p. 184).

The chapter about young Puerto Rican breast cancer patients where doctors rarely talk about the negative side effects of cancer treatments on fertility provides another example of the “clash of cancer cultures” and their respective emphases on individuals and families. Having a large family is a deep-rooted Puerto Rican value, and it is opposed to a dominant medical perspective that focuses on saving patient’s life, rather than their quality of life. The interviewed patients expressed their anger because their doctors had not discussed their options for preserving fertility. Their life philosophy does not revolve around satisfactory laboratory results. Similarly, the chapter on Mexican illegal immigrants shows them to be more fearful of losing their difficult, but hopeful life in the United States than living with untreated cancer. They are reluctant to go back to Mexico to get treatment because they might not be able to come back. Patients in India would rather spend their savings on children’s weddings or education, than on cancer treatment, because “group-sanctioned ambitions” are significant to the hierarchical “Indian self” (Dumont).

The two opposing models (Western-type survivor activism advocated by humanitarian sector and family-oriented model of support prevailing in India) continue through the post-treatment stage. The Western model is based on a new identity of “survivor” and willingness to talk about the disease and emotional experience with courage and pride, while the opposite approach is focused on the stigmatisation of cancer in a wider community, so the main strategy is to avoid talking about cancer or negative feelings related to the cancer experience. Although the first model seems to be more humane and patient-oriented by promoting “self-disclosure”, this approach may not always be beneficial in the non-Western context: ‘Talking *about* cancer is not necessarily perceived as a cathartic and therapeutic process but rather as a risky and morally dubious venture’ (p. 123).

Differences between the two cultural scripts are very prominent in the terminal stage of the disease. In the Western cultural script, death has become more shameful and tabooed than sex (Foucault 2012). According to the *sequestration* thesis (Walter, cf. Mathews 2015: 230), death is separated from everyday life by being medicalised, professionalised and de-spiritualised. Talking about death and dying is not encouraged.

Terminally ill patients in Scotland are ‘dying to be heard’, and their ‘dying is hidden, and its meaning privatized’ (Walter, cf. Mathews 2015: 230). In contrast, dying patients in Africa suffer less from existential issues compared to the “First World” patients, even as they struggle with excruciating physical pain and suffer in horrific conditions without adequate therapy. Kenyan patients are dying without adequate palliative care, often previously experiencing a series of incorrect or delayed treatments. Nevertheless, being surrounded by their social network, families and wider communities, they have better spiritual guidance in the critical stage, compared to people in affluent societies where death is professionalised.

However, cultural scripts are not homogenous. Situational diversities of childhood cancer within the “Western script” are well presented in Clemente’s study. Childhood cancer is very complex, because parents do not have an adequate cultural model for this situation (childhood cancers are rare), yet still must follow the dominant cultural model of childhood which emphasises child vulnerability while accepting that their children will go through difficult treatments. In Clemente’s study, two children died during his research. Paradoxically, a little girl aged five, who was dying from a kidney tumour, confronted death more readily than her mother. The girl wanted to talk about Jesus, crucifixion, angels, and heaven, and her mother realized that these were comforting bedtime stories for little Eli, although very upsetting for herself (Clemente 2015). This episode is contrasted with the Western cancer script of optimism and heroism that is the norm in childhood cancer treatment, and even more emphasised than in adult cancer in the context of the cultural model of childhood which emphasises children’s “futurity”, vulnerability and innocence, and the role of “biography guardians” (especially mothers) (Young 2002).

In the Western model, much focus is placed on establishing a scientific, optimistic and pro-active cancer worldview, and any kind of defeatism is not acceptable. As observed by a breast cancer survivor in Scotland, negative emotions expressed by patients are frowned upon (Mathews et al. 2015: 234). The same optimism is expected from those affected by childhood cancer (especially care-givers) and adult cancer: ‘The hero-survivor is the one who complies completely with biomedical treatments and fights against the odds to survive while maintaining a cheerful attitude’ (p. 28). A conflict between medical resistance to accept “defeat” and mother’s resistance to the continuation of suffering was evident in the case of Eli: doctors pushed for another treatment (with poor prognosis), and her mother resisted, but passively – she agreed with the doctor’s proposal, but did not appear with her daughter on the appointment day (Clemente 2015).

## **Cancer communication**

As Manderson has observed in *Anthropologies*, we are “surprisingly imprecise” in our communication about cancer:

We distinguish between Alzheimer’s disease, Parkinson’s disease, multiple sclerosis and motor neuron disease rather than speaking globally of neurological conditions, for instance; we treat as discrete – and make a point of establishing the difference – between a ‘common cold’ and other respiratory

tract infections. Yet cancer is cancer at first moment of diagnosis, and in telling. The differentiation comes later, to a smaller community, when clinicians, patients, family and friends all try to make sense of its emergence, determine intervention and assess the outcome (Mathews et al. 2015: 242).

Hundreds of cancer types are lumped together, but ‘cancer’ is ‘dense with metaphor’ (Manderson 2015: 242): *battling, survivors, warriors, thrivers, fighting spirit* (p. 3), *survivorship* (p. 7), *battleground, cancer and heroics, sainthood* (p. 231), *embattlement, struggles, victories, stealth and victimhood* (p. 242). These metaphors contribute to the essentialisation of a modern Western concept of cancer that focuses on accomplishments in “cancer wars”: decreased mortality rates, experimental therapies, improved palliative care, pain management, and victory over cancer.

The main purpose of cancer communication is to handle *uncertainties* as the most prominent aspect of the cancer experience (Clemente 2015). Cancer uncertainties can be associated with the present and with the future; there are local (ongoing treatment) and overall uncertainties; finally, uncertainties vary across cancer trajectories. In dealing with multiple uncertainties, sustaining optimism and hope is the norm. Clemente’s analysis shows that communicative strategies of medical authorities and parents are used mostly for this purpose: ‘To manage these different uncertainties, patients, parents, and doctors engage in the constant work of hope and optimism, in order to maintain a sense of certainty about the future’ (p. 21). Hiding negative emotions is a communicative strategy used for that purpose by parents and encouraged by doctors.

However, there are contradictions regarding the issue of *disclosing* diagnoses and prognoses when communicating with patients. On one hand, open communication, awareness and self-disclosure are encouraged in public discourse. On the other, patients in the terminal stage are silenced, because talking about death and dying is not encouraged. Clemente’s book focuses on disclosure as an integral part of cancer communication. Clemente distinguishes between ‘disclosure countries’ and ‘non-disclosure countries’, depending on the dominant approach to “truth telling”:

Non-disclosure is located within a traditional meta-narrative of ‘social embeddedness,’ with an emphasis on social unity, sparing another suffering and taking it on oneself, supporting a good life and a ‘good’ death, and the protection of society to ensure the adaptation of the community to life’s inevitabilities. Disclosure is located within a meta-narrative of ‘autonomy-control’ with an emphasis individual autonomy, control, and sovereignty of one’s destiny (p. 8).

Although disclosure officially replaced non-disclosure in communication with adult cancer patients in the 1970s, the change of paradigm is more complex than the question of ‘truth telling’ (Clemente 2015: 7). In *Anthropologies*, doctors in Kenya opt for non-disclosure to sustain patients’ optimism and determination to follow through with the treatment. This is very similar to the disclosure model used in communication with children.

Clemente applied the *prospective approach* to explore communication: communicative strategies and interactions were monitored as they unfolded along children's cancer trajectories. Thus, in addition to employing 'situated interactional data analysis' (Clemente, 2015: 42), his research has a longitudinal character. Clemente included children as active study participants in dialogues with medical staff and parents. In his explanation of micro-discursive subtleties of communication, Clemente used a "performative" approach to communication: 'Omission, silence, and other ways of not talking do communicate something, convey specific and situated meanings' (pp. xv, 5). Regulation of negative emotions, using silence and non-verbal communication are elements of Clemente's analysis. Language and communication are defined as *action*, in contrast to the "referentialist" position that focuses on the "referential role" of language. Language is used to "construct" social reality through interaction. The research was conducted on twelve young people aged 11–18 (with different cancer diagnoses) and five children aged 3–6. Most of the detailed conversation analyses were based on young people's conversations. The book contains drawings and linguistic explanations of selected situated conversations.

There are some similarities in cancer communication with adults and children. The name of the disease is avoided to control disclosure to the patient, and also as a defence mechanism by caregivers to alleviate their own anxiety. For example, Chinese patients are dying of 'vomiting illness' or 'choking or spitting illness' (referring to stomach and oesophagus cancers, respectively) (Mathews et al. 2015: 39). Children with cancer learn very early to avoid the word "cancer":

Suddenly, Pedro asked his parents: '... because it's *cancer*?' His mother answered, 'They've told you already. But you only have it here,' pointing to her own leg. The medical team and parents never used the word 'cancer.' Instead, they used 'lesion' or 'tumor'. Pedro's mother's use of the pronoun 'it' and her pointing gesture also allowed her to talk about 'cancer' without uttering the word. Pedro never asked his doctor if he had cancer. Indeed, I never heard Pedro use the word 'cancer' again (Clemente 2015: 2).

Communication in paediatric cancer is rife with ambiguity, because it is shaped by cultural expectations about children's autonomy and agency. Despite Western societies' shift towards children's participation, children do not participate in decisions about cancer treatment. Children are 'half-members, peripheral participants, and non-persons in healthcare interactions' and there is 'concealment of information from children with cancer and other life-threatening illnesses [...] in countries where disclosure is supposedly favoured, such as the United States and the United Kingdom' (Clemente 2015: 16–7; 13). Clemente identified six strategies used in communicating diagnostic/treatment information: deception, official and planned complete non-disclosure, unofficial leakage and gathering of information, unplanned and improvised partial disclosure, regulation of negative emotions, and official and planned partial disclosure. These strategies (some of them unintentional) vary across cancer trajectories: complete non-disclosure (with a possibility of leakage) is a norm before the diagnosis, while planned partial disclosure is practised during the treatment stage. Clemente observes that, the more uncertain the

future, the tighter the control of communication, which consists mostly of optimistic deception and complete non-disclosure.

Clemente emphasises two absences as guiding principles in communicating with children: absence of disclosure and absence of certainty. Most agents understand what is not acceptable, without being told (like Pedro): ‘Successful non-disclosure, like successful avoidance, evasion, and collusion, leaves no traces.’ (p. 45). The ‘conspiracy of silence’ in cancer communication manifests as a ‘conspiracy of talk’ (p. 6). Since silence would be interpreted by the participants as a sign of bad news, they rather ‘talk after a question without necessarily answering it, or prevent sensitive questions from being asked at all ...’ (p. 6). Also, talk about the distant future and prognosis is avoided, while a focus on the ongoing treatment is preferred: ‘focusing on what can be controlled and routinized (i.e., the everyday administration of treatment in the present moment) helps reduce uncertainty’ (p. 50). However, there is no clear distinction between disclosure and non-disclosure, telling and not telling. Children are actively trying to undermine the status of being passive recipients of information.

Children’s pursuits of questions and doctor’s evasions result in long ‘cat-and-mouse game’ negotiations regarding what to talk about and how. A child asked a question, a doctor evaded an answer, the child returned with a second question, the doctor gave some piecemeal information, the child asked a third question, the doctor light-heartedly teased the child, and so forth and so on. These ‘cat-and-mouse game’ negotiations also revealed that there was no exact agreement among participants at Catalonia Hospital on the limits of what needed to be avoided; they had different understandings of what needed to be avoided, and they collaboratively negotiated it (p. 46).

## Cultural universals

As we go through the chapters of these books, we become aware of different cancer cultures, cancer languages, and cancer uncertainties. At the same time, these two ethnographies show some universal anthropological features. The studies conducted in Western countries, such as France, Scotland (Mathews et al. 2015) and Spain (Clemente 2015) reveal the same desperation, resignation, and existential fear that we find in chapters about cancer experience in destitute conditions. Although the issues and struggles faced by cancer patients in the global “North” and “South” are nothing alike, a total self-disruption and existential uncertainty appear to be *cultural universals*. All cancer patients experience the so-called *biographical disruption* (the concept first used by Bury), suggesting that chronic illnesses like cancer cause ‘a threat to the individual’s established self-image, sense of agency and vision of the future’ (Mathews et al. 2015: 177).

Disruptive biographies have different manifestations in India and France, but they reflect the same anthropological invariant – fear of self and body deterioration. There is also a universal denial in dealing with biographical disruption although its manifestations are culturally specific. *Anthropologies* deals primarily with the non-Western context (chapters about Brazil and India), but Western media abounds with stories of survivors engaging in extreme endeavours that they would not even consider if they were healthy (running marathons). In less developed countries, patients tend to push their bodies in a

similar way, but for different reasons. As mentioned earlier, they tend to return to their life routine, suffering great pain and exhaustion.

The most persistent universal is related to the human horror caused by uncertainty (as shown in Clemente's work) and lack of control over the disease. All cultures search for the origin of cancer, either 'personal misdeeds' in non-Western countries or lifestyle choices and personality issues in Western countries. In both Western and non-Western cultural contexts, beliefs about the origin of cancer are manifestations of a desperate need to find the cure. Since there is still no cure, Western medicine focuses on the second-best option – prevention.

Prevention became the pivotal aspect of the modern medical approach to cancer during the 1990s when 'health became politicised' (Fitzpatrick 2000). The "tyranny of health" created a "new patient", with a high awareness of prevention and healthy lifestyles, in contrast to the old type of patients who seemed to be less anxious about longevity and health risks. Screenings are manifestations of this new perspective on health: 'the female body as an object in constant need of monitoring, evaluation and surveillance, a body for screening' (Kaufert 2000: 166–167). However, screening is not a patriarchal mechanism of women's oppression as it potentially includes everyone, depending on their family history, age group, gender, or lifestyle. Screening belongs to the *anticipatory habitus* (Mathews et al. 2015: 68). "A body for screening" is a new anthropological solution to human angst stemming from perceived lack of control over a dreadful disease, rather than an instrument of Foucauldian surveillance and control.

The limitations of Western prevention-focused cancer philosophy are clearly shown in *Anthropologies*. In Brazil, prevention is not available due to the lack of health insurance and physical access to health services in rural areas. Taking part in clinical genetic research is the only way for women at high risk of breast cancer (family history of aggressive cancer) to get access to regular check-ups. Similarly, in Kenya, prevention is almost non-existent, and late-stage diagnosis is dominant, due to lack of access to facilities, lack of medical expertise, or patients delaying examination and treatment.

While access to modern prevention techniques is unequal, prevention has a more universal anthropological meaning. It is part of the human search for cancer control. Lay and medical aetiologies of cancer focusing on "psychosomatic", "lifestyle explanations" or "moral misdeeds" similarly support the illusion that the disease is preventable.

## Cancer citizenship

Another inspirational concept used in the Foreword to *Anthropologies* is *cancer citizenship* (Mathews et al. 2015). Cancer citizenship is not global, as it, to some extent overlaps with politico-geographical boundaries. For example, cancers with infectious or environmental aetiologies are more common in the developing world (Mathews et al. 2015: 249). Cancer citizenship is valued depending on cancer type. Even in developed countries, patients suffering from cancers induced by lifestyle (lung cancer, cervical cancer) are deprived of "heroism" and get less financial support than breast cancer patients, because they are held responsible for their disease (Mathews et al. 2015: 28). Finally, cancer citizenship is not limited to those diagnosed with cancer: those at risk can also be considered



“cancer citizens”. As Klawiter observes (2008: xxviii), in the case of breast cancer, there is a ‘disease continuum’ that expands to all adult women.

*Cancer trajectories* (the concept used by Clemente) are different in childhood cancer and adult cancer. Today, a five-year survival rate for lymphoblastic leukaemia is 80%, compared to 0% in 1960 (Clemente 2015). A child survivor and an adult survivor prospects are different: cancer emerges when child’s identity is only being formed, while in adults there is a self-reflected ‘disruptive biography’ in place. Cancer trajectories also diverge across socio-economic and geo-political lines. A complex Western-type trajectory has many stages (“at risk”, “in treatment”) and new identities (“survivor”). Most of them are non-existent in non-Western/destitute social contexts. Most patients in Kenya never get to the stage of survivorship, because they are diagnosed too late. Stages have different lengths, so diagnosing and pre-treatment may be very long in Kenya, India, and among Mexican immigrants. The social stigma of cancer also prevents the development of survivor identity, even if there is an actual survival, because patients prefer not to create a new form of identity, as mentioned in the case of India (Mathews et al. 2015).

Rabinow’s concept of *biosociality* (used by Burke in *Anthropologies*) may be useful here as an umbrella concept for emerging social forms based on technological and scientific approaches to biology (Mathews et al. 2015; Rabinow 1992). In his seminal work, Rabinow anticipated new identities based on medical technology:

There will be, for example, neurofibromatosis group who will meet to share their experiences, lobby for their disease, educate their children, redo their home environment ... These groups will have medical specialists, laboratories, narratives, traditions and a heavy panoply of pastoral keepers to help them experience, share, intervene in, and ‘understand’ their fate (Rabinow 1992: 243–244).

To become recognised as social problems, issues must compete for attention and space on the public agenda (Lantz and Booth 1998: 909). For that reason, there are struggles among different “cancer communities”. There are many stakeholders involved in the world of cancer: patients, caregivers, policy makers, cancer lobby groups, governments, NGOs, IGOs, and pharmaceutical companies. For example, Klawiter (2008) claims that the breast cancer community has become the leading cancer community as a result of biopolitical strategies and lobbying. The result was an enormous increase in funding for breast cancer research over the last decades. Breast cancer survivors not only have a new identity but also act as political actors (Klawiter 2008). The politicisation of cancer is described in the chapter about Filipino breast cancer survivors in San Francisco. The local breast cancer support group was spontaneously created within the Filipino Community Group. It was funded by the national breast cancer foundation. However, the meetings were attended not only by breast cancer survivors but also by patients suffering from other types of cancer, or other diseases or even belonging to other ethnic groups. The donor opposed this and forced separation along “biological lines”, exclusive attendance of “breast cancer survivors” and allowed only discussions related to breast cancer, not even general health, even though there were breast cancer patients with other health issues.

(Mathews et al. 2015). The policy which forced biological identity over ethnicity seemed counterproductive in a group of people with intersecting health/ethnic identities.

Childhood cancers are different from adult cancers partly because children spend time in hospitals with their families and other children. Clemente describes a micro-cancer community in a paediatric hospital unit that ‘reproduced the social geography of a small Mediterranean village’ (Clemente 2015: 65):

The waiting rooms and playrooms were the village’s public squares, the hallways the streets, the hospital school was the village’s school with one classroom for children of all ages, and patients’ hospital rooms were private dwellings. Whenever a villager returns from an outside stay, he or she goes around the village paying visits to the houses of relatives and friends, checking who is also at home, inquiring about their well-being and also being updated about the latest news – and gossip – of the village (Clemente 2015: 65).

Children who died were remembered as members of a small “cancer village”. However, different cancer trajectories may cause distance between patients in remission and relapsed patients (Clemente 2015).

Gender is not the main topic of these two books, but its role is evident throughout most chapters. Clemente has noted that paediatric cancer is ‘largely a woman’s world’ (Clemente 2015: 41). Mothers were the predominant care-givers in the hospital, and medical staff were predominantly women (Clemente 2015). Other studies have shown the same pattern. Young and colleagues (2002) have found that majority of care-givers are mothers: they feel the obligation of *proximity*, the need to be physically close to the child with cancer. Gender bias is also evident in *Anthropologies*: most chapters focus on female cancer patients and caregivers. There are few chapters dealing with male cancer patients, but there again, the focus was on women as caregivers. The most discussed subject in *Anthropologies* is breast cancer, which is almost completely a gender specific disease. In *Afterwords*, Manderson says that half of all the chapters in *Anthropologies* are about breast cancer (Mathews et al. 2015: 243).

These two volumes bring to light some of the marginalised aspects of the cancer experience in the global North as well as South. The authors of *Anthropologies* have revealed the “subaltern” world of cancer experience and its variations across countries, but also within the “Western cancer world” (illegal Mexican immigrants in Arizona or Filipino community in San Francisco). Likewise, Clemente emphasises ‘intracultural diversity and dynamism, as well as contextual and individual variation’ of cancer (Clemente 2015: 7). The authors of both books demonstrated methodological advantages of anthropological approach for better understanding of universal issues of death, pain, physical deterioration, and social and emotional turbulence caused by cancer. In their efforts, the authors were mostly successful in playing the *cat-and-mouse game* with “the emperor of all maladies”.

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