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# Anthropology Book Forum

Open Access Book Reviews

## **At the Intersection of Medical and Linguistic Anthropology: Ethnographic insight into a Catalan Paediatric Oncological Ward**

**Review by Letizia Bonanno**

*Uncertain Futures: Communication and Culture in Childhood Cancer Treatment*

by Ignasi Clemente

Wiley-Blackwell, 2015

*Uncertain Futures* is an emotional and ethnographic journey in the paediatric oncological ward at the Catalonia Hospital in Barcelona. Ignasi Clemente offers a compassionate blueprint of what medical communication looks like when children with cancer, their families, and the medical staff struggle to make the trajectories of cancer and its treatment seem less uncertain. This ethnographic insight is offered through a captivating analysis of the communicative strategies that young oncological patients, their relatives and doctors engage in at the different stages of cancer treatment. Using extensive conversation excerpts to sustain his ethnographic inquiry, Clemente traces the dynamics and trajectories of the diagnostic process and the treatment children with cancer undergo and engage with on a daily basis.

Interestingly, Clemente focuses on describing how the everyday commitment to optimism seems to respond to a moral obligation to protect children from both the present and future suffering which might derive from the diagnosis of cancer or of treatment side-effects. In this vein, the commitment to optimism becomes apparent here through opaque communicative strategies, among which the notion of disclosure figures as both the theoretical knot and challenge that Clemente's volume revolves around. As illness and hope may both be embodied through talking, Clemente argues, chatting always implies and attunes itself to those moral discourses doctors and parents engage in with children on the necessity of their active and collaborative involvement in their treatment. Indeed a collaborative approach may

enhance the recovery, avoid relapse and make patients more aware of their condition. In this regard, awareness and compliant behaviors that patients are called to live through seem to resonate with the making of a neoliberal subjectivity, in other words, the moral making of future healthy adults able to care for themselves and increasingly able not to overburden the healthcare system. In this vein, Paul Brodwin (2012) and Elisabeth A. Davis (2012) have clearly highlighted how likely discourses on health are to blur with moralistic judgements on the patients' conduct by doctors, while attempting to enhance autonomy and responsibility in patients by stressing how the moral responsibility toward their own health actually implies being responsible toward others and society as a whole. How this transnational neoliberal turn has impacted in different ways on care practices and discourses was investigated in depth by Annmarie Mol (2008), who has in fact drawn attention to the contrasting logics of care and of the patients' choices, and has made apparent how the patients' free choices and good care are rarely a good combination.

Although the author repeatedly hints at how moral responsibilities are performed and fulfilled when it comes to care, Clemente does not broaden this perspective. A deeper grip on the anthropology of morality would probably have better enlightened how care is performed, enacted and experienced. In this sense, both Kleinman's hypothesis on care as a moral experience (2013) and Mattingly's concept of therapeutic emplotment (1991) would have provided Clemente with a broader perspective on care as a moral experience, as a narrative effort to make sense of the complex realities that illness brings about, and as the fulfillment of a moral obligation to maintain hope on a daily basis. In this regard, hope figures as one of the main knots in Clemente's ethnography, although he fails to problematize how hope is experienced and thought out by patients, and it is alternatively described as an on-going negotiation of the present as well as a future oriented attitude, as Zigon would put it (2009).

Nevertheless, by extensively interrogating the limits of verbal language, Clemente takes into consideration what roles are played by silence and postures, which are both graphically reported and rendered into regular conversation transcriptions and illustrations. The use of illustrations enriches the entire ethnography, and helps the reader better contextualise where and how verbal and non-verbal interactions take place. At the intersection of medical and linguistic anthropology, Clemente provides ethnographic cases throughout with which it becomes possible to critically rethink conversational dynamics occurring in medical settings and involving children. By relying on the methods of conversational analysis, the author contributes to implicitly challenge the axiom of power relations supposedly driving the encounter between patients and doctors. In so doing, an accurate perspective on

how medical authority is constantly faced and challenged by patients is offered by providing the reader with ethnographic vignettes. In this regard, Clemente defines the negotiation of information in order to highlight the different degrees of child participation in medical decision-making. Whereas a certain asymmetry in power between children, their family and doctors is undeniable, medical authority is often contested through non-collaborative behaviors or the relentless questions that young patients and their parents constantly confront doctors with. As such, the dynamic process of communication results as not just the expression of meaning, but also as the enactment of power. As it appears from reported conversations, strategically doctors tend to give patients cloudy and partial answers when patients' anxiety to know about their health condition mutate into a desperate need and search for certainties which are, however, beyond any medical predictability. Indeed, within the peculiar clinical context, the speculative nature of diagnosis couples with the ambiguity and duplicity of medical language and concurs to produce a situation of increased uncertainty and instability on the patients' side. Nevertheless, symptoms and speeches together constitute a language of the body through which patients express a range of dispositions, conscience and critique towards the medical authority and knowledge.

Beyond linguistic analysis, *Uncertain Futures* also focuses attentively on how cultural factors, medical knowledge and emotional talks intertwine. Taking full advantage of his proximity with the Spanish culture and languages, Clemente provides a unique perspective on making the hospitalization process for children with cancer as favorable as possible, and brilliantly depicts how life intersects in different ways with treatment at the Catalan Hospital. Clemente shows how the routinization of hospital life makes the paediatric ward look like a 'small village', a temporary microcosm of social relations which are daily negotiated, made and undone through friendships, love, reciprocity, shared perplexities and personal experiences which are always on the verge of becoming collective. Worth noticing is how fear and negative emotions are stubbornly kept in the private sphere as they are felt to threaten children's wellbeing and the parents' commitment to optimism. As a consequence, the parents' emotional bursts of despair, which generally happen far from the others' eyes, parallel the apparent quietness of the paediatric ward, while signaling what Clemente indicates as the process of becoming a parent of a child with cancer. In this sense, Clemente's argument seems to resonate with Addlakha and Das' definition of 'domestic citizenship' (1998).

Although the feeling of *togetherness* stemming from the ward results from the proximity that the ward seems to forcibly enhance by its very nature as a place of confinement, children's parents seem to take

relief from their becoming closer to each other. Whereas proximity contributes to the production of lay and practical knowledge which derives from sharing and exchanging experiences and helps parents to cope with their children's symptoms and suffering, equally it allows parents to better cope with those changes that their children's hospitalisation has brought in their daily lives. Indeed, life is seemingly suspended in time and place: many of them have in fact quit their jobs to take care of their children, others have left their villages to move to Barcelona so as to follow their children's hospitalisation more closely. In the effort of rebuilding a daily routine, proximity helps them redefine the terms of parenthood and personhood.

*Uncertain Futures* definitely provides original insight on how patienthood and childhood are experienced when illness reshapes the terms and meanings of time and hope for both children and their kin. Navigating the ups and downs of cancer treatment is mirrored in temporal discontinuities in the ordinary life of the ward – waiting for examinations results or for the side effects of their treatment to become evident – and changes the experience of time which is not only felt to be escaping them, but often experienced bodily through a slow but relentless deterioration of health conditions. From a phenomenological perspective, the body becomes the hinge of experience and through an attentive reading of symptoms and signs, coping strategies and predictions of diagnosis and treatment developments may be inferred as well. Although Clemente is well aware of the role that time plays in articulating the trajectories of illness and recovery, the texture of ethnographic and clinical time often results in a disjointed reading experience, and the potentials of ethnography do not seem to be completely scrutinized. Furthermore, frequent theoretical digressions scattered throughout the volume render the whole ethnographic picture slightly fragmented.

Clemente's work undoubtedly opens up broader margins of reflection about how medical diagnoses, and in general medical communication, are delivered and negotiated and provides the reader with extensive references with which the theoretical discussion is constantly confronted and challenged. *Uncertain Futures* is a complex text which actively engages with the legacies informing the author's framing of the lives of young cancer patients and their relatives. In so doing, Clemente is surely paving the way toward a more fertile and effective collaboration between medical and linguistic anthropology, which might mutually benefit from theoretical contamination.

## **References Cited**

Addlakha, R. and Das, V. (1998) *Disabilities and Domestic Citizenship: Voice, Gender and the Making*

of the Subject. *Public Culture* 13(3)

Brodwin, P. (2012) *Everyday Ethics: Voices from the Front Line of Community Psychiatry*. University California Press

Davis, E. A. (2012) *Bad Souls. Madness and Responsibility in Northern Greece*. Duke University Press

Mattingly, C. (1991) The Narrative Nature of Clinical Reasoning. *The American Journal of Occupational Therapy* 45(11): 998- 1005

Mol, A. (2008) *The Logics of Care: Health and the Problem of Patient Choice*. Routledge Paperback

Kleinman, A. (2013) From Illness as Culture to Caregiving as Moral Experience. *The New England Journal of Medicine* 368(15): 1376- 1377

Zigon, J. (2009) Hope dies last. Two Aspects of Contemporary Hope in Moscow. *Anthropological Theory* 9(3): 253-271

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