WORKSHOP ABSTRACT

Transition in Health

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Abstract: Anthropology has long been preoccupied with transition. Transitions, famously captured by Van Gennep's "rites of passage" or Turner's concept of "liminality", punctuate human life, which is embedded in culture and society. Transition may also serve as a lens to analyze change and adaptation in society (e.g. Hasan 2023) and was extensively used in the context of postsocialism (e.g. Buyandelgeriyn 2008). Building on this long-standing tradition of anthropological engagement with the concept of transition, this workshop invites social science, in particular ethnographic contributions focusing on spatial, structural, and temporal aspects of transitions in the medical field. In medicine, transition is e.g. understood as a "multi-dimensional process, involving patients, caregivers, providers, and the medical system as a whole" (Cheng et al. 2021). Due to the development of medical technologies and treatment modalities, an increasing number of people with chronic and/or rare diseases reach adulthood and experience a transition from pediatric to adult care (Jae 2018). In some instances, this is uncharted territory for both patients and care providers. Transitions, as passages of change, may also be experienced on a mundane level by patients who change their dietary and/or drug regimens or by health personnel who climb the medical career ladder. We encourage ethnographically grounded analyses that address both large-scale transitions and mundane moments of transition in health and healthcare. We are also interested in papers examining failed transitions or transitions that had to be abandoned.

SESSION SCHEDULE

Tuesday, September 24, 2024 | Slot 3 | Room 5
Karine Aasgaard Jansen: Transition in menstrual health: From hygiene to human right

Kristine Krause: Care transitions, housing positionalities and anticipation work

Christina Dam Jacobsen: Halfway Home – An anthropological study of a discharge unit in the Danish Regional Psychiatry

Laila Rajani: Psychiatry in a time of flux: notes from an outpatient psychiatry clinic in Tharparkar, Pakistan

Julia Demirdizen: "It's more about living than dying" - Volunteers' perspectives on childhood, death and care in Berlin

Eva-Maria Knoll: Stuck in the pediatric ward: Shortcomings in thalassaemia transition in the Maldives

Tuesday, September 24, 2024 | Slot 4 | Room 5

Malgorzata Rajtar: "First survivors": Uncertainty, anticipation, and transition in rare metabolic disorders

Virginie Córdoba-Wolff: A socio-anthropological approach of the passage towards becoming gluten-sensitive

Katinka Weber: Reflections on the Potential of a Community-Based Arts Intervention in Mali to TransformFood Hygiene and Child Nutrition Practices

Jasmina Polovic: From Disordered Worlds to Disordered Minds: Mental Health Epidemic in Postsocialist Slovenia

Kriss Fearon: Women with Turner syndrome (TS): pushing back against the stigma of medically-managed transitions

SESSION PAPERS

Transition in menstrual health: From hygiene to human right
<u>*Karine Aasgaard Jansen*</u>

Each day, around 800 million people are menstruating across the globe. Menstrual health refers to "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in relation to the menstrual cycle" (The Global Menstrual Collective, 2021). While this definition shows how menstrual health is essential to the wellbeing of more than half of the world's population, menstruation is nevertheless often subject to various cultural taboos and rarely talked about in public.

Both within the medical field and in a classical anthropological sense, transitions related to menstruation are primarily understood to reflect girls' and women's reproductive cycle from menarche to menopause. Menstruation is thus perceived as marking a cultural and societal life stage transition into or out of biological reproductive capacity. In various parts of the world, something seems to be stirring when it comes to periods, however. Over the last decade a burgeoning global movement of activists, NGOs, civil society organisations and international organisations has pushed menstruation into the public eye, and made it matter beyond the individual bodily experience. Periods have become political. Yet, while advocacy and mobilisation around menstrual health is increasing, we are simultaneously facing a worldwide pushback again sexual and reproductive health

and rights (SRHR).

Against this background, I will explore why menstrual mobilisation addresses menstruation as a human right rather than as a hygiene issue, and what risks and possibilities this transition from the personal to the political in menstrual health may entail. The presentation draws on a coming research project focusing on menstrual activism- and justice. Since the study is yet to be realised, the aim of the talk is to raise questions for further debate while simultaneously contributing towards removing stigma by breaking the silence on menstruation.

Care transitions, housing positionalities and anticipation work
Kristine Krause

Increasing care needs in later life can require spatial transitions in terms of housing. In this contribution, we analyze the transitions between different positionalities that emerge around (transnational) housing, due to increasing care needs. Our case study is an Assisted Living (AL) facility in Hungary that mainly target clients from Germany and Switzerland. Based on the portability of social rights as well as economic differences within Europe, it offers seniors a life on their own, but with help at hand and the possibility to relocate to a nursing department within the same facility when needed. Most residents have previously lived in Hungary as retirement migrants, enjoying a good life with lower costs of living and their own houses with big gardens. However, when becoming older, having lost a partner, these houses became a burden and the AL facility appeared as a solution. While the autonomous, self-determined elderly subject is questioned through the emerging care needs, the assisted living positionality enables self-management at the boundary between independence and dependence, and exerting control over certain aspects of living (e.g., managing professional services) in a situation of loss of bodily or mental capacities of redefining autonomy by assigning greater value to control over little aspects of daily life. The residents thereby engage in anticipation work in which they plan for a future yet to come and securing it in the presence. Key features of controlling that future is to perform a constant boundary drawing and controlled crossing between the bungalow area (which is the area of AL) and the main house (which is the space of the nursing home and nursing care). This boundary drawing happens in many different ways and moments and is interrelated with outsourcing parts of the responsibility and decision making around transitions to professionals.

Halfway Home – An anthropological study of a discharge unit in the Danish Regional Psychiatry
Christina Dam Jacobsen

This study is based on a 4-month fieldwork and investigates the patients' experiences with a Danish psychiatric discharge unit, focusing on home and homeliness, the transition between psychiatric hospital and home and temporality. The paper suggests that home and homeliness are created through everyday rhythms and routines, recognizability, freedom, materiality, belonging, relations and the security that follows. These characteristics are based on the homeliness of the psychiatric unit and stand in contrast to how the patients describe their home. The paper examines the binary opposition

hospital/home and how the discharge unit enables homeliness through its position in-between. Further arguing that what separates home from homeliness at the discharge unit is the temporary characteristic of the hospitalization. This paper shows how the patient's home during hospitalization develops from being the ideal and goal to becoming a threat as discharge approaches. It critiques how the ward in their work with the patients transition to home only manage to take care of parts of establishing a good transition, whilst relational aspects and security are not established in the context of the patient's home. The discharge unit is in the paper portrayed as a gap (mellemrum) in the transition to home, as a result of its position between psychiatric hospital and home and the blurred boundaries this position entails. Finally, this paper suggests that as the home shifts from being ideal to becoming a threat to the patients, their narrative structure regarding their admission changes as well. Previously, it followed the caretakers' structure: Admitted --> discharge unit --> discharged. Now, however, it becomes more complex as the ward, once seen as a homely and safe environment, becomes a fixed part of the patients' narrative. The structure thus changes to: Home --> admitted --> discharge unit as admission unit.

Psychiatry in a time of flux: notes from an outpatient psychiatry clinic in Tharparkar, Pakistan
Laila Rajani

The rising numbers of suicides in Tharparkar district in southern Pakistan are often explained by local actors through the lens of Tharparkar's rapid and unequal transition to modernity and technological advancement through the advent of regional corporations (China Pakistan Economic Corridor) and local private institutions (Sindh Engro Coal Mining Company). The mental health programmes in response to these alarming suicide rates mirror this transient nature of Tharparkar in their effort to popularise new therapeutic interventions, grounded in the new national trends of privatisation of healthcare surrounding digital psychiatry and pharmaceuticals.

In this paper, I engage with how these transitions in mental healthcare materialise in the everyday experiences of a psychiatry outpatient clinic (colloquially psych OPD) at the Civil Hospital, Mithi, the biggest medical facility in Tharparkar and surrounding districts. The psych OPD is touted as an example of a successful public-private partnership, bringing together public health infrastructure and private funding and advocacy in a 'sustainable' way. Although the clinic's successful run since 2017 shows a promise towards bringing psychiatric care to Tharparkar, it also raises questions about the politics of care that is heavily predicated on pharmaceutical and individualist principles of privatisation of health in the absence of systemic and structural alternatives. Using data from interviews and observations conducted at the hospital over the course of my doctoral fieldwork, I aim to understand which agendas and interests are served by the popularising of pharmaceutical-heavy psychiatry that celebrates itself on the grounds of 'partnership-led'.

With expanding fossil fuel extraction and changing landscape of Tharparkar, the psych OPD clinic becomes a pivotal space to examine how transformations in healthcare reflects the changing material and political realities of the region, and what continuities

and disjunctures mark this dynamic.

"It's more about living than dying" - Volunteers' perspectives on childhood, death and care in Berlin
Julia Demirdizen

The above quote was given by Leila, a volunteer who works to support and accompany a family with a child diagnosed with a life-threatening illness.

While palliative care is a well-established sub-discipline of biomedicine and is perceived as helpful assistance towards the end of life, the idea of children facing death and dying is echoed with silence or avoidance.

Faced with silence and avoidance, 'parents whose children had received a life-shortening prognosis came together for the first time out of disappointment and frustration at being isolated in society and left alone with this issue' (Jenessen 2011: 7). In 1990 they founded the German Children's Hospice Association and gave the movement a starting point in Germany. Today there are 19 inpatient and around 230 outpatient children's hospices in Germany (Deutscher Hospiz- und PalliativVerband e.V.:2023).

Children's hospices are only partially funded by the state, so the work of volunteers, also known as civic engagement, is essential. Families can use the outpatient services provided by volunteers free of charge. Volunteers support and engage with families and their children on a weekly basis. They become enmeshed in the lives of the families, forming a caring community and advocating for greater visibility in society.

Based on six months of fieldwork from October 2022 to March 2223 in Berlin with four volunteers caring for children and young adults, the paper explores how they navigate the new carescapes within families, what kind of transitions they describe, and how they perceive their new roles.

The volunteers' perspectives offer a lens into the vulnerable lifeworlds of families and help to understand the dimension of negotiating a sustainable quality of life in anticipation of death.

Stuck in the pediatric ward: Shortcomings in thalassaemia transition in the Maldives
Eva-Maria Knoll

Thalassaemia ranks among the most common inherited blood disorders in South Asia. Over the last two decades progress in biomedical treatment and biosociality have allowed for the transition of thalassaemia from a fatal pediatric disease to a chronic condition. Although treatment options are limited compared to those in affluent Western countries, 20-40% of thalassaemia patients are reaching adulthood in South Asia. Yet, any guidance through the biomedical and social passage from the pediatric ward to adult care through structured transition of care programs is largely missing.

In the Maldives the number of adult thalassaemics also is growing though they seem to

struggle to escape the pediatric sphere of care and to satisfactorily change their status. The concept of transition has already gained significance in the Rare Diseases realm but is absent in the Maldives. This is remarkable and alarming since the island nation has the highest rate of beta thalassaemia carriers in the world. Based on ethnographic data this paper argues the urgent need for a transition of care policy for Maldivian thalassaemics and discusses the spatial, structural, and ideological obstacles and barriers to such a process of change from pediatric to adult care.

"First survivors": Uncertainty, anticipation, and transition in rare metabolic disorders
Malgorzata Rajtar

Inherited metabolic disorders (IMDs) constitute a large and heterogenous group of rare genetic diseases that are characterized by impaired biochemical functions of metabolism. Historically, IMDs were considered a domain of pediatric discipline. IMDs are highly fatal if not diagnosed early. Due to better screening, diagnosis, and treatment options, the number of people with IMDs reaching adulthood has increased, especially in the Global North. Yet, when transitioning from pediatric to adult care, these "first survivors" (Gariani et al. 2020) face an unknown future that is characterized by a shortage of adult specialists and knowledge about their IMD as well as uncertainty that impacts their daily lives.

This paper draws from ethnographic research conducted among people with specific IMDs and/or their caregivers in Finland and Poland (2016-2023). While most research participants were parents of newborns and/or children with IMDs, here I primarily focus on two adults with IMDs who may indeed be called "first survivors" in their countries: Kalle in Finland and Zofia in Poland. Revered by the current local biosocial communities for their ability to survive during the era when no newborn screening was offered, Kalle and Zofia were nonetheless left to negotiate their transition and the progress of their disease with healthcare professionals, educators, and employers by themselves. In this paper I examine those negotiations and I analyze how, despite being diagnosed with the same IMD and facing similar uncertainties related to long-term outcomes of the disease, their transition into adulthood has differed.

A socio-anthropological approach of the passage towards becoming gluten-sensitive
Virginie Córdoba-Wolff

On the basis of ethnographic observations and interviews conducted during my PhD in sociology (2017-2022), in and around Paris, in the Grand Est (France) and in Berlin-Brandenburg (Germany), involving 62 people, including 50 who are avoiding gluten, I sought to grasp what leads people to adopt this diet, focusing on what I called the 'passage towards becoming food sensitive', a theme I propose to discuss in this paper. While bringing together the sociology and anthropology of health, of the body and of food, I have constructed the concept of 'passage' using a number of theoretical tools - including Abbott's 'turning point' (2009), Van Gennep's rite of passage (1909) - first taken up by Turner (1990) and by Saillant (1988) then by Soum-Pouyalet and Hubert (2011) - to emphasise the processual dimension of settling into the diet and the way in which gluten

sensitivity is experienced and lived, but also to stress the liminal dimension of the start of the diet.

The transition towards becoming gluten-sensitive highlights three phases: the pre-diet, the start of the diet (or the liminal phase) and the affirmation of the diet.

This segmentation highlights the fact that commitment to the diet is a process often marked by periods of medical wandering. This passage is experienced as a solitary struggle, full of doubts and uncertainties. The path to a diagnosis, when there is one, sometimes takes several years.

Certain dispositions, life experiences and biographical moments seem to encourage people to "act out", i.e. to become gluten-sensitive. In addition to certain socio-demographic characteristics, the transition to gluten sensitivity often begins at times of transition, or even at times that are experienced as chaotic (studies, competitions, long-term stays abroad). In addition, joining the diet is sometimes a catalyst for professional transitions, as well as changes in circles of acquaintances.

Reflections on the Potential of a Community-Based Arts Intervention in Mali to TransformFood Hygiene and Child Nutrition Practices
Katinka Weber

MaaCiwara is a randomised control trial in Mali (2021-24) run by Malian and UK university partners, evaluating a low-cost, community-level, behaviour-change intervention to reduce infant diarrhoea and malnutrition. As similar programmes have struggled to achieve lasting results, MaaCiwara takes a novel 'positive-motivational' rather than 'disease-focused' approach, using performing arts (singing, storytelling, etc.).

Drawing on data from the project's process evaluation (2023-24) (72 focus groups in 12 communities and observations), here we consider, firstly, whether a focus on transitions can provide us with a lens through which to analyse the dynamics involved in communities' adopting/ rejecting the behaviours promoted by the project and, secondly, the potential for the interventions' theatre components to enhance uptake/acceptance. While, as in other global health projects, there is scope for clashes between project-promoted behaviours, values and understandings of disease and 'local' understandings, our findings suggest more nuanced processes.

Overall, the intervention was well-received, and participants saw merits/health benefits in applying the messages. In several communities, intervention vocabulary and imagery are becoming the subject of Malian 'joking kinship', thereby not only becoming embedded into daily language via jokes, stories, and singing intervention songs, but forming part of the production and reproduction of social bonds. Especially powerful/suggestive is the language and imagery relating to the two contrasting female theatre characters which spectators emotionally identify with: a mother applying the project-promoted standards of food-hygiene and child-nutrition and another (played by a man) who does not. This supports findings of the team's realist review which demonstrated the effectiveness of theatre as motivator in health projects primarily due to the emotional response they stimulate. Understanding the relationship between projects and people requires a nuanced engagement that considers affective and socio-economic aspects, moving local people's agency to the centre; an ethnographic focus on transitions could provide us with

an appropriate analytical lens.

From Disordered Worlds to Disordered Minds: Mental Health Epidemic in Postsocialist Slovenia
Jasmina Polovic

My contribution is grounded in a 3-year fieldwork and clinical work as a psychological and psychiatric anthropologist with Slovenians diagnosed with newly emerging mental disorders within a postsocialist context. I use newly emerging mental disorders as an umbrella term that encompasses particular psychiatric diagnoses (adjustment disorder, depression, anxiety disorder) and clinically recognized Western idioms of distress (burnout) that have either emerged or skyrocketed after the social change in postsocialist Slovenia. Such conditions display distinct illness narratives and embodiment of distress that are inherently connected not only to core local values but also to the Slovenian concept of personhood. As the social change introduced certain practices and social institutions that are in discontinuity with Slovenian culture and criminalize the ones that are locally perceived as right and just, Slovenians find themselves in disabling, yet existentially important situations. In such circumstances, Slovenians are exposed to certain social encounters (a specific type of interpersonal encounter in the modern Slovenian workplace and an encounter with the state where the responsibility to mend the disruptions and structural violence is transferred from the state onto the individual) for which they lack the cultural capital to deal with within their cosmological world. I demonstrate how the Slovenian experience of transition is reflected in the mental health epidemic following the social change. I also show the importance of including anthropological knowledge in mental health services by identifying the cultural within the psychological and show how introducing cultural factors into my clinical practice has severely reduced the use of medicaments and sped up recovery and reintegration with the "patients" I overview.

Women with Turner syndrome (TS): pushing back against the stigma of medically-managed transitions
Kriss Fearon

Turner syndrome (TS) is a rare chromosome disorder affecting 1:2500 women; girls are usually born without ovaries, impacting their physical development and fertility in adulthood. Slow growth may be treated with growth hormone, puberty may be initiated with oestrogen, while women may have children via IVF. Oestrogen supplementation is explicitly given 'to mimic normal timing and progression of physical and social development' (Klein et al, 2018). Hence the key life transitions of puberty, menarche, and becoming a parent, 'paradigmatic markers of life experience' (Halberstam, 2005) are controlled with medication, and their timing is medically managed.

This paper explores how these key transitions are managed by women with TS and their families in a context where 'chrononormativity' (Freeman 2010: 3) is socially expected. Thus, as girls and women are 'bound into socially meaningful embodiment through temporal regulation', temporal misfitting with peers can be stigmatising. Kafer's (2013) concept of 'crip time' illuminates how women and girls with TS addressed, circumvented

and normalised the timing challenges of these transitional points. It also discusses how mothers of girls with TS managed transitions, given their own experience of mothering misfit in comparison with peers with children whose growth and social development aligned with expected milestones.

This paper is taken from a wider study which used photo-elicitation interviews within a constructivist grounded theory framework to explore reproductive choice with 19 women with TS and 11 mothers of girls with TS in the UK.