Re:visit
Humanities & Medicine in Dialogue

Discursive practices of human-machine relations in diabetes management

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Recent post-humanist theories challenge the notion of human superiority and see humans in constant interaction with and dependence on their material and natural environments.[1] Part of these material environments are rapidly developing new technologies, such as AI-supported medical engineering, and biotechnology. They are blurring the lines between the human and the non-human and put anthropocentric thinking up for debate as technology increasingly shapes the way we think about, feel, and speak about the world.[2]

This relation of humans with their technological environments is especially striking and essential in medical contexts: Medical diagnoses nowadays can hardly do without technical equipment, mini-robots assist in surgical procedures, organ and limb functions are supported or controlled by machines and their associated algorithms, such as cardiac and brain pacemakers, dialysis or diabetes management.[3] Technologies are radically changing the way medical professionals think about and interact with patients' bodies; they are also drastically changing the way how people who use the technologies perceive their own bodies and interact with the devices in their daily lives. Engaging with medical technologies therefore has not only health-related but also social and cultural implications.

1 See Florian Cord: Posthumanist Cultural Studies: Taking the Nonhuman Seriously. In: *Open Cultural Studies* 6.1 (2022), 25-37.

2 See Marco Dehnert, David J. Gunkel: Beyond Ownership: Human–Robot Relationships between Property and Personhood. In: *New Media & Society* (31 July 2023); Alastair Pennycook: *Posthumanist Applied Linguistics*. London, New York 2018; Bruno Latour: *Reassembling the Social: An Introduction to Actor-Network-Theory.* Clarendon Lectures in Management Studies. Oxford 2007.

3 Heike E. Krüger-Brand: Technisierung der Medizin: „Die Technik ist uns auf den Leib gerückt". In: *Deutsches Ärzteblatt* 111.50 (2014), A2208-A2212. https://www.aerzteblatt.de/pdf.asp?id=165615 (14.9.2024).

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In this vein, the research project "Discursive practices of human-machine relations in diabetes management" aims at a deeper understanding of human-machine relations by investigating diabetes management through algorithm- and AI-supported technologies from a discourse-linguistic point of view.[4] Diabetes management is a particularly promising field for exploring human-machine relations as there is a steady stream of technological innovations that facilitate the regulation and control of blood glucose levels for people with type-1 diabetes who require continuous insulin supply. Very recently, automated insulin delivery (AID) systems – often referred to as an 'artificial pancreas' or hybrid loop – have been officially approved for the market. In these systems, algorithm-driven insulin pumps communicate directly with continuous glucose monitors (CGMs). This happens with little or even without human intervention to reduce or increase insulin delivery as needed.

From a clinically medical and often quantitative point of view, research abounds on the efficacy of these new technologies, particularly on 'time in blood glucose range' of people with diabetes.[5] However, the relational aspects between humans and machines in these contexts are rarely considered and consistently lack qualitative approaches that prioritize the subjective and complex perspectives of users. Recent anthropological and sociological research has focused on showing human-technical relations in this field particularly as practices of constant self-surveillance or practices of quantification in organizing daily life according to blood glucose levels.[6] Mol and Law's[7] study as another example on the qualitative spectrum of disease-related research describes patients' ways of 'doing' their bodies when experiencing hypoglycaemia. They elaborate how medical care needs to account for the complexity in the daily lives of people with diabetes by not reducing their bodies and the disease to numerical glucose levels. However, these existing qualitative

4 See Barbara Johnstone: *Discourse Analysis*. Third edition. Hoboken 2018; Jürgen Spitzmüller, Ingo Hans Oskar Warnke: *Diskurslinguistik: Eine Einführung in Theorien und Methoden der transtextuellen Sprachanalyse.* Berlin 2011.

5 See Steven Russel: Multicenter, Randomized Trial of a Bionic Pancreas in Type 1 Diabetes. In: *New England Journal of Medicine* 387.13 (2022), 1161-1172. doi: 10.1056/NEJMoa2205225; Armaan Nallicheri et al.: Review of Automated Insulin Delivery Systems for Type 1 Diabetes and Associated Time in Range Outcomes. In: *Endocrinology* 18.1 (2022), 27-34. doi: 10.17925/EE.2022.18.1.27

6 See Lisa Wiedemann: *Self-Tracking: Vermessungspraktiken im Kontext von Quantified Self und Diabetes.* Wiesbaden 2019; Aaron Pfaff: Die Stoffwechselselbstkontrolle – von der Harnzuckerbestimmung zur digitalen Blutzuckermessung. In: Sabine Wöhlke, Anna Palm (eds.): *Mensch-Technik-Interaktion in medikalisierten Alltagen*. Göttingen 2018, 129-143; Barbara Frischling: Digitale Selbstvermessung und die (Re-) Produktion von Ordnungen im Alltag. In: Wöhlke and Palm (eds.), Mensch-Technik-Interaktion, 117-128.

7 See Annemarie Mol, John Law: Embodied Action, Enacted Bodies: The Example of Hypoglycaemia. In: *Body & Society* 10.2-3 (2004), 43-62. doi: 10.1177/1357034X04042932.

studies rarely address the profound every-day relations of humans with their diabetes technology devices.

There is, then, a large research gap in the medical humanities regarding the impact of recently approved AID systems that are attached to the body and automatically deliver insulin to the patient, as well as on the users' perception of this increasing agency of machines in diabetes management. This is why this research project is based on a qualitative and ethnographic perspective that is considering discursive accounts of users talking about their daily interactions with the machines.

Based on these premises, three broader lines of inquiry are followed in this research project. The first one deals with questions regarding the transformations of *human bodies* in everyday interactions with diabetes devices. People using this technology for the management of their diabetes are in continuous and existential corporeal contact with the devices: Typically, a pump is connected to the body via a catheter and a needle while an adhesive glucose sensor is attached to the body. As part of the project, I'm analysing how the participants talk about their bodies in relation to the devices, how the relations of their bodies to the disease of type-1 diabetes transform with the devices as interlocutors and where and how bodies 'start' and 'end' with devices being attached to them, transgressing or forming part of the bodies. The second line of questions in the project focuses on aspects of human and machine *agency*. The research uncovers if and how the medical devices are considered to be agentive – following an understanding of agency as "the socioculturally mediated capacity to act"[8] – as they form a vital part of the everyday interactions and practices of the people (co-)operating with them. Thirdly, I'm looking at the relation of discursive accounts to *social practices*[9] in the field of technically assisted diabetes management. In triangulating interview data with ethnographic observations and online interactions, the project will identify common themes and how they interlink with situated real-time interactions of people with type-1 diabetes with their devices.

These broad thematic lines culminate in the following research questions:

1. How do participants using AID systems talk about their devices and their everyday interactions with them?
2. How do participants speak about their own bodies in relation to the devices?

8 Laura M. Ahearn: Language and Agency. In: *Annual Review of Anthropology* 30.1 (2001), 109-137, 112.

9 See Andreas Reckwitz: Grundelemente einer Theorie sozialer Praktiken. Eine sozialtheoretische Perspektive. In: *Zeitschrift für Soziologie* 32.4 (2003), 282-301.

3. How do the participants evaluate the machine‘s agency and relate it to human agency in diabetes management?
4. How do discursive practices of human machine-relations intersect with social categories like gender, age, technological affinity, or the type of technology used?
5. How do discursive practices in negotiating diabetic human-machine relationships link to social practices in the diabetic community as well as to those of medical professionals?

Discourse linguistics

The theoretical and methodological starting point to approach these research questions lies in the emerging field of discourse linguistics[10]. Discourse linguistics examines the ways in which language is used in social interactions to create meaning and shape social reality.[11] The term discourse thus needs to be understood as language in use that relates to specific forms of knowledge in "constructing a particular version of reality"[12]. Both the content of what participants say and the discursive form that they choose to talk about certain topics are of interest for this discourse analytical inquiry. The analysis of linguistic form is based on different levels of language description such as morphology, syntax or semantics.[13] Furthermore, since the data consists of interactional discourse, the sequential unfolding of the speakers' use of categories and different voices in talking about their everyday practices with the devices are examined.

This linguistically informed approach gains a deeper understanding of discursive practices of human-machine relations in two ways: First, it provides insights into the speakers' conceptualizations of machines, bodies, their interrelationships and agency; second, by considering the sequential unfolding of these conceptualizations in interaction, the actual complexities and contradictions of negotiating meaning can be traced.[14] Thus, the aim of this project is to uncover the discursive practices of talking about humans, machines, and their relations in diabetes management. The concept of discursive practices is essential for

10 See Spitzmüller and Warnke, Diskurslinguistik; Constanze Spieß: *Diskurshandlungen: Theorie und Methode linguistischer Diskursanalyse am Beispiel der Bioethikdebatte*. Berlin, Boston 2011.

11 See Johnstone, Discourse Analysis.

12 Deborah Cameron, Ivan Panović: *Working with Written Discourse*. Los Angeles 2014, 17.

13 See DIMEAN model by Spitzmüller and Warnke, Diskurslinguistik, 201.

14 See Rita Tamara Vallentin: *Language and Belonging: Local Categories and Practices in a Guatemalan Highland Community*. Berlin, New York 2019, 58-59.

understanding how a) human-machine relations are (re-)produced in discourse, b) how identities and social hierarchies are constructed and reproduced across different contexts and forms of interactions[15], and c) how participants' positionings, especially along the lines of gender, influence talk about human-machine relations. Therefore, this qualitative study puts discursive practices and the interactional making of (re-)negotiating 'the human', the 'body', and the 'machine' as well as their respective perceived agencies and subjectivities centre stage.

Participatory Research Design and Methodology

The research project is based on three different data sets that are analytically triangulated to gain an informed insight into discursive and social practices in the field. The main corpus for the analysis consists of 35 qualitative in-depth interviews in German that were collected between March 2022 and September 2023. The participants are people who manage their type-1-diabetes with an AID system and who thus use both insulin pump and CGM. They were recruited by calls for participation on websites for clinical studies and diabetes blogs. The interviews were conducted following ethical standards ensuring informed consent, confidentiality, and anonymity of all participants. In the interviews, the participants speak about their daily life with the devices, the perception of their bodies and evaluations of the machines' agency in diabetes management. Additionally, questions of trust in the technology and possible shifts in the role of 'human' agency in diabetes management are addressed.

The second data set consists of mainstream online discourses in the diabetes community. Two of the biggest German platforms for information on all aspects around type-1 diabetes are the webpages *diabetes-online.de* and *blood-sugar-lounge.de*. By analysing blogposts and comments on new AID technologies for diabetes management, I relate findings from the interview data to larger and public discursive practices on these devices and on the relations between humans and machines in diabetes care. Comparing discursive practices in the interviews and in digital blog posts ensures accounting for different interactional contexts and therefore the triangulation and adequacy of the analysis. Both data sets are inductively categorized, identifying the main topics and themes in the corpora. The different topical fields are studied with the fine-grained method of ethno-

15 See Rita Tamara Vallentin: Linguistic Practices. Theoretical Approaches and Empirical Findings. In: Mônica Savedra et al. (eds.): *Repertórios plurilíngues em situação de contato.* Rio de Janeiro 2019, 112-118.

graphically informed conversation analysis[16] regarding their discursive (re)productions of particular categories, positionings and attitudes.[17]

The triangulation of the interview data is complemented by participant observation from medical conferences and (digital) group meetings of the diabetic community. This enriches the findings on discursive practices in the interviews and on the digital platforms with insights into discursive and social practices related to technologically informed medical care and community-specific action 'in the wild'.

Emphasizing aspects of research validity and transfer into the diabetic and medical community, one specific analytical driving force is participatory research[18] in form of a data sprint[19]. A mixed group of different stakeholders of the research comprised of participants from the interview group, medical professionals in diabetes care, and further linguistic experts will collaboratively do analytical work with fully transcribed and precoded data from the interview corpus to gain new perspectives on the data and enhance the rigor of the analysis. These stakeholders are also part of a collaborative effort to develop a guideline for healthcare professionals on patient experiences with diabetes technology. Thus, the project outcomes will not only contribute to pressing questions of social and cultural studies regarding post-humanist thinking about bodies and agency but also to practical medical care ensuring a better understanding of user perspectives and thus, different forms of informed doctor-patient-communication regarding AID systems.

Tentative results

Bodies and Devices

After having completed the data collection phase the analysis allows for first tentative results regarding the second and third research question focusing on the discursive constructions of bodies and agency in relation to the medical devices within the qualitative

16 See Arnulf Deppermann: Ethnographische Gesprächsanalyse: Zu Nutzen und Notwendigkeit von Ethnographie für die Konversationsanalyse. In: *Gesprächsforschung – Online-Zeitschrift Zur Verbalen Interaktion* 1 (2000), 96-124.

17 See Vallentin, Language and Belonging, 56-64; Mary Bucholtz, Kira Hall: Identity and Interaction: A Sociocultural Linguistic Approach. In: *Discourse Studies* 7 (2005), 585-614; Stephen Hester, Peter Eglin: Membership Categorization Analysis: An Introduction. In: Stephen Hester, Peter Eglin (eds.): *Culture in Action. Studies in Membership Categorization Analysis.* Lanham 1997, 1-23.

18 See Michael T. Wright, Jane Springett, Krystyna Kongats: What Is Participatory Health Research? In: Michael T. Wright, Krystyna Kongats (eds.): *Participatory Health Research*. Cham 2018, 3-15.

19 See Tommaso Venturini, Anders Munk, Axel Meunier: Data-Sprinting. In: Celia Lury et al. (eds.): *Routledge Handbook of Interdisciplinary Research Methods.* London 2018, 158-163.

interviews. Regarding the first topical field the analysis shows that devices are either constructed as 'foreign objects' (*Fremdkörper*), or as 'parts of the body' (*Teil des Körpers*).[20] The first conceptualization of 'foreign objects' becomes specifically evident when looking at prepositions and adverbs participants use when talking about the devices. They are 'on' the body (*am Körper*), 'attached to' the body (*dran*), something that can be 'put on' or 'taken off' (*an- und ablegen*). The physical integrity of the body can be penetrated by the devices as shown in linguistic constructions like 'stuck in' (*drin stecken*) or 'tear out' (*raus reißen*). In these accounts, bodies, like devices, are linguistically construed as 'objects' bounded by an external barrier, the skin, and experiencing various forms of direct contact with or violation of their own integrity by devices. It is noticeable that the interviewees use a strong technical vocabulary in describing these 'objective' bodies for example as 'coupling pieces' (*Kupplungsstücke*). The second conceptualization of the devices as literal 'parts of the body' recognizes bodies as being 'broken' (*kaputt*) in their own capacity to produce insulin cells and thus in need of repair by the devices as a kind of organ substitution or prothesis. Both the body and the device are part of an objectified assemblage of tissue and mechanical material. Participants often verbalize these body-device relationships in terms of being 'cyborgs' or 'robots'.

What the first results also show is that apart from 'objectified' bodies the participants also linguistically construct 'feeling bodies' that experience themselves in relation to the devices. These experiences of bodies as *Leib*[21] conceptualize the relations to the medical devices as metaphorical and situated 'incorporations' (*Einverleibungen*) in which the devices become part of the interviewees' identities[22] and determine the ways in which they conceive of their own bodies.

Agencies and Devices

Regarding the second topical field preliminary results comprise remarkable negotiations of agency in diabetes care between people with type-1 diabetes and their devices. In modern AID-systems insulin pumps are in constant connection with glucose sensors and –

20 See Rita Tamara Vallentin: Erste Ergebnisse einer Interviewstudie zur Selbstwahrnehmung von Menschen mit Typ-1-Diabetes. *Diabetes Congress Reports* 2 (2023), 23-24.

21 See Maurice Merleau-Ponty: *Phänomenologie der Wahrnehmung.* Berlin 2010.

22 See Reinhold Esterbauer: Leib – Körper – Maschine. Zum Problem der leiblichen Aneignung technischer Artefakte. In: Walter Schaupp, Johann Platzer (eds.): *Der verbesserte Mensch.* Baden-Baden 2020, 29-44.

depending on the model and manufacturers – regulate insulin delivery or cutting it off completely automatically. These systems lead to less frequent human interventions and open up questions of trust, control and agency for the users. After a first data review it becomes evident that the devices are linguistically framed as agentive by the interview participants as their actions are often described with verbal phrases of different processual types[23]: the insulin pump 'says' things (*sie sagt*), 'intervenes independently' (*sie greift eigenständig ein*) and is 'forgiving (human) mistakes' (*sie verzeiht Fehler*). As a device conceptualized close to or even as part of the body that is able to perform actions on its own based on algorithmic programming it is anthropomorphised as a collaborator or co-manager in the daily task of keeping the blood sugar in check. All in all, these first glimpses into analytical results reveal highly complex relationships between humans and their AI- and algorithm-based medical technology.

Further analytical work in this project will deepen and consolidate these first insights and elaborate the complexity of medically necessary human-machine relationships, how they are discursively accounted for in different interactional contexts and how they materialize in situated social practices.

Impacts

Overall and as visible from the first analytical results, the project connects to larger post-humanist questions by exploring what it means to be 'human' in the context of a medically essential human-machine interaction, and how participants linguistically rework the boundaries between themselves and the devices. Focusing on these "assemblages"[24] between humans and their medical devices not only contributes to the emerging field of post-humanist linguistics, but also connects to medical research on diabetes technology from a discourse-linguistic perspective that seeks a stronger focus on patient perspectives and experiences. By listening to how people with type-1 diabetes speak about their every-day experiences with the technology, the medical community can account for the intricacies and complexities of interactions with medical devices, as well as how people with type-1 diabetes perceive their bodies in relation to the devices and how exactly

23 See M. A. K. Halliday, Christian Matthiessen: *Halliday's Introduction to Functional Grammar*. 4th edition. London, New York 2013.

24 Pennycook, Posthumanist Applied Linguistics, 13.

they manage their daily lives with them.[25] Such knowledge is crucial to improve technologically assisted diabetes care and possible challenges in acceptance, especially when we consider the ever-increasing initial manifestations of the disease.[26]

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25 See Vallentin, Erste Ergebnisse einer Interviewstudie zur Selbstwahrnehmung von Menschen mit Typ-1 Diabetes; Mary Bucholtz, Kira Hall: Embodied Sociolinguistics. In: Nikolas Coupland (ed.): *Sociolinguistics*. Cambridge 2016, 173-198.

26 See Daniel D'Souza et al.: Incidence of Diabetes in Children and Adolescents During the COVID-19 Pandemic: A Systematic Review and Meta-Analysis. In: *JAMA Network Open* 6 (2023), e2321281. doi: 10.1001/jamanetworkopen.2023.21281.