

„Illness narratives in practice“

26.-27.6.2015

Abstracts

Institut für Psychologie
Universität Freiburg

Organization:

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Using narratives in medical training

Prof. Dr. Alexander Kiss

Clinic of Psychosomatic Medicine
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In my talk I will focus on how narratives are used in the training of medical students at the medical faculty of Basel.

Narratives are used for training of the so-called basic competencies of Communication and Medical Humanities.

The learning goals are that the doctor is a good listener, a good story teller, and is sometimes able to create an illness narrative together with his or her patient. For this, communication techniques are necessary.

Medical Humanities in Basel consists of mandatory and voluntary elements. In the first year, there are mandatory courses on film and medicine, in the second year, on literature and medicine. In the third year, voluntary courses on mindfulness and transcultural competence are offered. In the fourth year, when students work in a GP practice, they are obliged to write an essay about a patient (reflective writing, e.g. "please write about a patient for whom you felt little or no empathy"). In the fifth year, when students do practical work in different hospitals, an internet forum to reflect the work experience by written essays is offered. For all elements, I will give examples to illustrate the use of narratives in medical training in Basel.

Alexander Kiss studied medicine in Heidelberg and Vienna. He worked in Vienna at the Psychosomatic Unit of University Clinic for Psychiatry and had his Psychoanalytic Training at the Vienna Psychoanalytic Society. He qualified as a University lecturer in 1990 for Internal Medicine at the University of Vienna. In 1994, he was appointed Professor of Psychosomatic Medicine at the Universitätsspital of Basel, Switzerland, where he lectures in medical Humanities. In 2006, he received the Prize of the Swiss Cancer League for program of communication skills training for oncologists

Retelling one's life story - Using narratives to improve quality of life in case of chronic illness

Prof. Dr. Sabine Corsten

Department for Health Care and Nursing
Catholic University of Applied Sciences
Mainz, Germany

Research in the field of narrative based medicine showed the efficiency of using illness narratives to stimulate coping processes. Following this, we developed an interdisciplinary biographic-narrative approach to improve Quality of Life (QoL) in persons with aphasia, a neurological language disorder. Aphasia leads to a change in self-perception and a diminished QoL. However, only a few studies use life story work in aphasic patients because of the language deficits (Bronken et al., 2012; Shadden & Hagstrom, 2007). We target identity renegotiation through an adapted biographic-narrative intervention.

27 participants with chronic aphasia were enrolled. The intervention consisted of five face-to-face in-depth interviews and seven group sessions conducted over 10 weeks in a pre-post-test-design and a follow-up assessment three months post-intervention. According to our hypotheses, we found a significant and stable improvement in QoL demonstrating the benefits of using narratives. The transferability of the intervention to other patients has to be discussed.

Bronken, B.A., Kirkevold, M., Martinsen, R., & Kvigne, K. (2012). The Aphasic Storyteller: Coconstructing Stories to Promote Psychosocial Well-Being After Stroke. *Qualitative Health Research, 22*(10), 1303–1316.

Shadden, B.B. & Hagstrom, F. (2007). The Role of Narrative in the Life Participation Approach to Aphasia. *Topics in Language Disorders, 27*(4), 324-338.

*The current work is supported by a grant of the German Federal Ministry of Education and Research (BMBF, FKZ 17S10X11)

Sabine Corsten studied teaching and research in speech therapy and now she works as a Professor in speech and language therapy at the Department for Health Care & Nursing at the Catholic University of Applied Sciences Mainz. She has done research and published on topics in Neurological Communication Disorders.

Friday, 26.6., Afternoon session, Lecture Hall

Using illness narratives in clinical diagnosis: The example of narrative reconstruction of epileptic and non-epileptic seizures and panic attacks

Prof. Dr. Elisabeth Gülich

Universität Bielefeld

Germany

This talk will outline some of the results of two interdisciplinary research projects concerning the subjective accounts patients give of their illness in doctor-patient interaction. It is based on a corpus of about 130 encounters with patients suffering from epileptic or non-epileptic seizures and/or anxiety disorders, for most of whom differential diagnosis is very difficult. The basic assumption is that the types of narrative can give clues to identify the types of seizures or attacks.

The focus will be on the “methods” patients use in verbalising the “auras” preceding the seizures and the course of the seizures or attacks themselves. In particular attention will be paid to the procedures of resolving difficulties of verbalisation, which may occur during the production of the narrative.

It can be shown that preferences in the choice of narrative techniques allow a distinction of patients with epileptic seizures from patients with other types of fits or with panic attacks.

It is argued that knowledge of recurrent narrative patterns can help to recognize the presented syndrome, on condition that the doctor encourages narrative reconstructions and that s/he listens carefully. Thus illness narratives, especially if recorded, transcribed and closely analysed, are a suitable instrument for differential diagnosis in practice.

Elisabeth Gülich studied French, Latin and Physical Education at the Universities of Freiburg, Vienna and Kiel. “Staatsexamen” in 1964, Kiel. Research and teaching assistant at the University of Cologne, doctor’s degree in 1969. “Habilitation” in 1976 at the University of Bielefeld. Professor of text linguistics at the German department of Freie Universität Berlin (1979-1981). Chair of Romance Languages and Linguistics at the University of Bielefeld (1981-2002). Research in text linguistics, namely in narrative analysis, and in conversation analysis. Current research interest in medical communication, working with interdisciplinary research teams, mainly with medical researchers, on patients’ illness descriptions and narratives. Principal aim: contribute to differential diagnosis by linguistic analysis.

Narratives – an underestimated instrument in the rehabilitation of patients with neurotrauma

Dr. Peter Frommelt

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10783 Berlin
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Conventional rehabilitation after neurotrauma, e. g. stroke, traumatic brain injury, has been influenced by a restorative medical model in which separate cognitive and emotional domains are addressed in the therapeutic interventions. It has been criticized that the socio-cultural and biographical context are neglected and that the shattered self of the injured person is insufficiently reflected in rehabilitation practices. There is evidence that a context-sensitive approach is providing better long-term outcomes regarding participation in life. The key instrument to contextualize neurorehabilitation and to support reconfiguring the self is the narrative. Even severely impaired patients provide either by themselves or through a vicarious voice, either elaborated or fractionized, either with or without words a self. The narrative is instrumental for a) providing meaning to therapeutic tasks, b) a scaffolding for reconstruction of self and identity c) involving significant others,d) providing hope. The narrative is part of practice which can be characterized as “logic of care” within a context –sensitive rehabilitation model (Frommelt, 2010).

Peter Frommelt studied medicine at Freiburg University and trained in Neurology, Psychiatry and Rehabilitation. From 1988-2011 he was Head of the Department of Neurorehabilitation, Asklepios-Klinik Schaufling. Since 2011 he works in private practice for neurorehabilitation in Berlin. Together with Jens Brockmeier and Maria Medved, he organizes since 2012 the annual “Berlin Symposium on Narrative Medicine”, the third will take place on 08.08.2015 with the topic “Narrative Perspectives”. His topics of interest are narrative based Neurorehabilitation, models of context-sensitive rehabilitation, goal setting in neurorehabilitation, and narrative and the model of the International Classification of Functioning, Disability and Health (ICF). Publication: Editor with Hubert Lösslein: NeuroRehabilitation, 3rd. ed Springer Publ. 2010.

The Role of Narratives in Ethical Counseling

Prof. Dr. Hille Haker

Richard McCormick S.J. Endowed Chair of Catholic Moral Theology
Loyola University
Chicago, USA

Ethics is the reflection of moral values held by individuals and norms mediated by different social settings. Ethical counseling addresses moral conflicts concerning the decision-making. While non-directive counseling emphasizes the moral agency of the individual and calls for the respect of the person seeking counseling, ethical counseling turns to the moral dimension of the situation in question. Narrative ethics is one way to bridge the experiences and values, on the one hand, and the moral norms that govern the decision-making, on the other. The lecture introduces a model how to integrate a narrative ethics approach as part of the ethical counseling, ensuring that both individual experiences and the normative dimensions of responsible actions are maintained.

Hille Haker holds the Richard McCormick S.J. Endowed Chair of Catholic Moral Theology at Loyola University Chicago. Having earned her dissertation and habilitation at Tübingen University, Germany, she previously taught at Harvard Divinity School, Cambridge/Ma, and Frankfurt University, Germany. She is a member of the European Group on Ethics in Sciences and New Technologies to the European Commission (EGE) since 2005. Her books include *Moralische Identität. Literarische Lebensgeschichten als Medium ethischer Reflexion* (1999), *Ethik der genetischen Frühdiagnostik* (2002), *Hauptsache gesund* (2011), and several co-edited books, among them: *The Ethics of Genetics in Human Procreation* (2000), *Ethik-Geschlecht-Wissenschaften* (2006), *Medical Ethics in Health Care Chaplaincy* (2009), and *Religiöser Pluralismus in der Klinikseelsorge* (2014).

Issues of sampling and generalizability in research on narratives

Prof. Dr. T horsten Meyer

Professur für Rehabilitationsforschung

Institut für Epidemiologie, Sozialmedizin und Gesundheitssystemforschung

Medizinische Hochschule Hannover, Germany

A thoughtful and well-founded sampling strategy in qualitative research is a prerequisite of generalizability and, therefore, of the quality of qualitative research. The sampling strategy can be determined a-priori (purposeful sampling) or integrated into the analysis process (theoretical sampling). One important criterion is to reach maximum variation of the phenomenon under study. Also, the selection of the cases or citations to be reported should be compatible with the research aim and, therewith, the sampling strategy. Relating this line of argument to the use of illness narratives, I make the point that in the selection of narratives for practice we should overcome the temptation to select those cases or citations that fits the practical purpose best, as can be found in journalism or politics. My argument is, however, based on the concept of analytical generalization rather than the concept of transferability (cf. Polit & Beck 2010), the latter offering other freedoms in the selection of cases.

Thorsten Meyer studied psychology in Kiel, Germany. He did his Phd on perceptions of schizophrenic persons of quality of life. From 1996 to 2010, he was researcher at the Justus-Liebig-University Gießen and the Institute of Social Medicine, University of Lübeck. His Habilitation thesis was on issues of variation in medical rehabilitation in people with low back pain. In 2010 he became leader of a research group at the Swiss Paraplegic Research. Since 2011 he holds a professorship on rehabilitation research at the Institute for Epidemiology, Social Medicine and Health Systems Research, Integrative Rehabilitation Research Unit.

Saturday, 27 th of June, Morning session, Lecture Hall

Understanding and using patients' experiences to improve healthcare

Prof. Sue Ziebland

Health Experiences Research Group (HERG)
Nuffield Department of Primary Health Care Sciences.
Green Templeton College
Oxford, UK

We contend that it is insufficient to collect data (whether by narrative or through self-completion questionnaire surveys) on patient experience: it should also be used to improve care.

Since the year 2000 the Health Experiences Research Group (HERG) in Oxford has studied a hundred different health conditions and collected nearly 4,000 narrative interviews. In this talk I will draw on our experiences of applying these qualitative interview studies to improve health and care. I will discuss some of the issues that arise when using this sort of material for secondary analysis and present some examples to demonstrate that patients' narratives can be used successfully to improve understanding of what matters to patients and to support improvements in health and care.

Sue Ziebland is Professor of Medical Sociology and director of the Health Experiences Research Group (HERG), based in the Nuffield Department of Primary Health Care Sciences. She is also a senior research fellow at Green Templeton College and an NIHR Senior Investigator.

www.phc.ox.ac.uk/team/researchers-n-z/sue-ziebland

Sue has worked as a researcher in the academic, NHS and voluntary sectors and has published over 150 papers and chapters in social science and health publications. She has led the research for the Health Talk projects since the projects started in 2000 and is now seeking funding to study how DIPEX International might support colleagues to learn from patients' experiences in low and middle income countries.

Narratives and medical decision-making

Dr. Christine Holmberg, M.P.H., MA

Berlin School of Public Health
Charité-Universitätsmedizin
Berlin, Germany

In this paper I will bring together anthropological approaches to learning and understanding narratives as experience-near accounts with considerations of the role of narratives in patient decision-aids. Including patients in medical decision-making has come to be seen as an important feature of current health care delivery. To help patients understand the options they have, the development of appropriate patient information (PI) and decision-aids (DA) is critical. Often such tools include narratives. Their use in PI/DAs is under debate: 1.) the selection or construction of narratives remains opaque, 2.) their effect on patients' decision-making is unclear, and 3.) they may have an undue influence on decision-making. Narratives as a source to understand health care decisions in context, helps explain what void the fill in DAs/PIs. The "need" for narratives in DA/PI speaks to the importance experience has on decision-making. Understanding the epistemological underpinnings of narratives may aid a more reflective use of narratives in improving health care decision-making.
Dr. phil. Christine Holmberg, M.P.H., M.A.

Christine Holmberg holds a Dr. phil. from the Humboldt-University Berlin in Anthropology and a Master of Public Health in Epidemiology from the University of Illinois at Chicago.

She is founding director of the research group on "health services research - qualitative and mixed-methods approaches" at the Berlin School of Public Health, Charité-Universitätsmedizin Berlin. Her research interests include health decision-making, illness experience, and knowledge circulation. Projects have been funded by the German Ministry of Education and Research and the National Cancer Institute, USA among others.

Saturday, 27 th of June, Morning session, Lecture Hall

Stories, illness and narrative norms

Prof. Lars-Christer Hydén

Dept. of Social and Welfare Studies

Director of Center for Dementia Research (CEDER).

Linköping University, Sweden

Collecting and using illness narratives has become an established practice among social science researchers in the medical field as a way to explore illness experiences. In the lecture the role of narrative norms will be discussed, that is, the norms that often are taken for granted about how a narrative should look in order to be counted as a narrative and as researchable. Autobiographical illness stories are for instance generally supposed to be coherent and true. Many persons, especially with neurocognitive disorders, have problems living up to and adhere to these narrative norms, thus telling stories that risk being considered as non-stories or as incoherent and fragmented stories. A number of examples of conflicts between narrative norms and illness stories will be discussed. In conclusion it is argued that researchers must use data collecting methods as well as analytical strategies that allow for alternative ways of telling stories.

Lars-Christer Hydén received his PhD in Psychology from Stockholm University, Sweden. His current position is as full professor of Social Psychology at Linköping University, Sweden, and as director of Center for Dementia Research (CEDER). His research primarily concerns how people with Alzheimer's disease and their significant others interact and use language – especially narrative – as a way to sustain and negotiate identity and a sense of self.

Some critical comments on illness narratives in use

Dr. Janka Koschack
Prof. Dr. Wolfgang Himmel
Institut für Allgemeinmedizin
Universitätsmedizin Göttingen
Germany

Illness is a call for stories as Arthur W. Frank (1995) put it. And, indeed, there are many studies that underpin the power of storytelling as a way of 'meaning making' for ill people. It is also widely accepted that a narrative approach in medicine and nursing improves health care outcomes. Moreover, there is the assumed but still not proven idea that listening to illness stories of others has a positive effect also on fellow patients. Analysing an interview example from our German DIPEX website, we first want to show how DIPEX websites arrange illness narratives. The most striking feature of these websites is that stories are not presented as a whole, but are fragmented to short statements and summarized under certain topics. Second, we want to start a discussion about how and for which purpose website visitors probably use these fragments of illness narratives.

Janka Koschack is working as a psychologist at the Department of General Practice at the University Medical Center Göttingen for over ten years. One of her research interests is how to assess and integrate the patient perspective in evidence-based medicine. She is one of the co-founders of the German DIPEX website www.krankheitserfahrungen.de. For further information: http://www.allgemeinmedizin.med.uni-goettingen.de/de/media/contact/CVE_Koschack_2013.pdf

Wolfgang Himmel is working as a sociologist at the Department of General Practice at the University Medical Center Göttingen. His research interests include health services research, Internet and patient-oriented information, physician-patient relations, social pharmacology and sociological research methods to be used in primary care and medical education research. He is one of the co-founders of the German DIPEX website www.krankheitserfahrungen.de. For further information: http://www.allgemeinmedizin.med.uni-goettingen.de/en/media/contact/CVE_Himmel_2013.pdf

Illness narratives in use: an overview

Prof. Dr. Gabriele Lucius-Hoene

Abt. für Rehabilitationspsychologie und Psychotherapie
Institut für Psychologie der Universität

Prof. Dr. Cornelia Helfferich

Institut für Soziologie der Universität
Evangelische Hochschule
Freiburg, Germany

As the congress shows, illness narratives are used for a broad variety of clinical purposes from teaching to diagnostics, therapy, building relationships and support or decision making. The authors try an overview of the many faces and uses of illness narratives in different contexts. Their main goal is to point out how the context of narrative interviewing or narrative communication about illness, the linguistic and communicational properties of the resulting stories as well as the strategies, stakes and interests of creating and using narratives are closely interconnected and very often remain underdetermined and opaque. The authors make an argument for thoroughly analyzing these contexts and aspects of how illness narratives were generated and to which goals they are meant to contribute before deploying them or regarding them as a sort of magic bullet within a holistic approach to patients. In a more unspecific and broader perspective qualitative analysis of the whole body of narratives shows illness as a collective representation and the “social form of told illness”: It reveals not only what can be told about illness, but the limitations of communication as well.

Gabriele Lucius-Hoene is a psychologist and a medical doctor at the Department of Rehabilitation Psychology and Psychotherapy of Freiburg University. Besides teaching qualitative methods and linguistically oriented methods of narrative analysis as well as doing clinical work as a neuropsychologist and psychotherapist for brain-injured patients, she has been interested in narrative medicine and narrative research in sociolinguistics and psychology. Her focus is on narratives als coping devices. Gabriele is one of the co-founders and researchers of DIPEXGermany with its website www.krankheitserfahrungen.de.

Cornelia Helfferich is a sociologist at the Protestant University of Applied Sciences, Freiburg, and the Department of Sociology of Freiburg University, and head of the Institute for Social Science Research on Women and Gender, Freiburg, SoFFI F. She regularly carries out research projects involving qualitative methods, focusing for instance on narratives of violence and abuse or biographic narratives. She is teaching methods for collecting and analyzing qualitative data.

Saturday, 27.6., Afternoon sessions

Session 1: Room SRA, Lecture Hall Building, 1st floor

Workshop:

Das Ungreifbare vermitteln – Krankheitsnarrative in semi-narrativen Interviews mit HIV-Patienten

Dipl. Psych. Alexandra Gross M.A.

Lehrstuhl Germanistische Linguistik
Universität Bayreuth
Germany

Deutsch/German

Die Diagnose von HIV wird in Erzählungen HIV-positiver Patient/innen häufig als plötzlich ins Leben einbrechendes Ereignis dargestellt. Der Plötzlichkeit der HIV-Diagnose als einschneidendes Erlebnis zuwiderlaufend ist das Fehlen der physischen Erfahrbarkeit der HIV-Infektion: Sie selbst ist (abgesehen von bisweilen auftretenden Nebenwirkungen der ART-Medikation) asymptomatisch und lediglich an der Menge der HI-Viruslast sowie am Immunstatus in Form abstrakter Zahlwerte „ablesbar“. Was Patient/innen über ihren persönlichen Zugang zu ihrer Erkrankung im Verlaufe ihrer Krankheitsgeschichte berichten, spiegelt dies wider.

Für den Workshop geplant ist eine Datensitzung nach konversationsanalytischem Vorbild:

- Präsentieren ethnographischer Hintergrundinformationen zum Projekt und zu den Gesprächsdaten
- Präsentieren von offenen Fragen „an die Daten“
- Gemeinsames Anhören der Daten und Einbringen erster Beobachtungen durch Teilnehmende des Workshops
- Fokussierung auf einzelne Abschnitte im Datum: sequenzielle Analyse mit Fokus auf sprachlich-interaktive Vermittlungsverfahren in Bezug auf die subjektive Repräsentation, biographische Erfahrung und/oder (alltägliche) Erfahrbarkeit von HIV.

Alexandra Groß hat an der Universität Freiburg Psychologie (Dipl.) und Sprachwissenschaft des Deutschen (M.A.) studiert. Seit 2012 ist sie wissenschaftliche Mitarbeiterin am Lehrstuhl Germanistische Linguistik an der Universität Bayreuth. Im Rahmen ihres Promotionsprojekts mit dem Arbeitstitel ‚Arzt/Patient-Kommunikation mit HIV-Patient/innen in Deutschland‘ untersucht sie Arzt/Patient-Gespräche mit Methoden der Gesprächsanalyse und setzt einen Fokus auf die Frage, wie sich die als (wissens)asymmetrisch geltende Gesprächsbeziehung zwischen HIV-Mediziner/innen und Patient/innen angesichts der chronischen Krankheitsbedingung bei HIV ausprägt. Ihre Interessengebiete sind u.a. Wissen-in-Interaktion, medizinische Kommunikation und Konversationsanalyse.

Projektvorstellung: Kinder erzählen von Krankheit und Tod von Angehörigen

Dr. Heike Knerich

Fakultät für Linguistik und Literaturwissenschaft
Universität Bielefeld, Germany

Deutsch/German

Dr. Miriam Haagen

Praxis für ärztliche Psychotherapie für Kinder, Jugendliche und Erwachsene
Hamburg, Germany

In unserem Vortrag stellen wir zunächst das Projekt „Trauernde Kinder“ in seiner Anlage und Ausrichtung vor. Nach einem kurzen Abriss des Forschungsstands vergleichen wir zwei bereits vorliegende semistrukturierte Interviews. Dabei legen wir den Schwerpunkt auf die narrative Rekonstruktion des Tages der Todesnachricht. Im ersten Fall handelt es sich um eine ausführliche biographische Rekonstruktion durch einen betroffenen Jugendlichen, die von der Interviewerin durch einen Erzählanreiz angeregt und mit Rezeptionssignalen unterstützt wird. Im zweiten Fall rekonstruieren die Therapeutin und die interviewte Jugendliche den Ablauf der Ereignisse gemeinsam: Die Interviewerin unterstützt ihre Gesprächspartnerin mit Rückfragen und Reformulierungen. Ausgehend von der Betrachtung der narrativen Rekonstruktion in diesen Gesprächen diskutieren wir dann die Darstellung bzw. Relevanz von Krankheit des verstorbenen Angehörigen in den vorliegenden Fällen. Abschließend stellen wir die ersten Ergebnisse und die weitere Projektkonzeption zur Diskussion.

Heike Knerich ist Mitarbeiterin im Arbeitsbereich Sprache und Kommunikation bei Prof. Dr. Barbara Job an der Fakultät für Linguistik und Literaturwissenschaft, Universität Bielefeld. Nach dem Studium Magister Germanistik, Literaturwissenschaft und Biologie, Universität Bielefeld promovierte sie an der Universität Dortmund zum Thema „Vorgeformte Strukturen als Formulierungsressource beim Sprechen über Angst und Anfälle“ publiziert 2013 beim Logos Verlag, Berlin. Seit 2004 ist sie Mitglied einer interdisziplinären Arbeitsgruppe zu Arzt-Patient-Kommunikation mit besonderem Fokus auf diagnostischen Fragen. Derzeitige Forschungsprojekte fokussieren institutionelle Gespräche mit Kindern und Jugendlichen. Ihre Interessengebiete: Gesprächsforschung, Kommunikation von Emotionen (speziell von Angst), psychotherapeutische Interaktion, Arzt-Patient-Gespräche, institutionelle Gespräche mit Kindern und Jugendlichen, Vorgeformtheit / Phraseologie.

Miriam Haagen ist Fachärztin für Kinder- und Jugendmedizin, ärztliche Psychotherapeutin tiefenpsychologisch fundiert für Kinder, Jugendliche und Erwachsene und psychoanalytische Paar- und Familientherapeutin. Sie nahm an einem Interviewprojekt zu Lebenswirklichkeiten von Familien in drei Generationen unter der Leitung von Dr. med. Antje Haag teil. Bis 2004 war sie stellvertretende Leiterin der Beratungsstelle „Kinder körperlich kranker Eltern“ am Universitätsklinikum Hamburg-Eppendorf. Von 2002-2004 wurde das Forschungsprojekt „COSIP children of somatically ill parents“, unterstützt durch eine EU-Forschungsbeihilfe von der Hamburger Arbeitsgruppe geleitet. In diesem Rahmen wurden zahlreiche kinder-, jugendlichen- und familienbezogene Interventionen entwickelt und die diesbezügliche Begleitforschung sichergestellt. Seit 2005 arbeitet sie in eigener Praxis für ärztliche Psychotherapie für Kinder, Jugendliche und Erwachsene in Hamburg und ist als Dozentin und Supervisorin für verschiedene Weiterbildungsinstitute sowie für die Fortbildungsakademie der Hamburger Ärztekammer (psychosomatische Grundversorgung) tätig. Sie ist Mitglied im Fortbildungsbeirat der Arbeitsgemeinschaft für integrierte Psychoanalyse, Psychotherapie & Psychosomatik Hamburg e. V., im Beirat der Zeitschrift psychoanalytische Familientherapie und Mitglied im Vorstand der Thure von Uexküll Akademie für integrierte Medizin.

**Krankheitserzählungen in der politischen Kommunikation.
Instrumentelle, institutionelle und soziale Funktionen von
Pathographien politischer Akteure**

Matthias Bandtel, M.A.

Fachbereich Human- und Sozialwissenschaften,
Abteilung Soziologie
Arbeitsgruppe Soziologie der Politik
Bergische Universität Wuppertal
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Deutsch/German

Der Vortrag analysiert veröffentlichte Krankheitserzählungen von deutschen Bundes- und LandespolitikerInnen aus den Jahren 2009 bis 2012. Dabei wird den Fragen nachgegangen, aus welchen Gründen politische Akteure eigene Krankheiten publik machen, welche Deutungen von Krankheit und Politik ihre Pathographien anbieten und wie sich die mediale Präsentation kranker PolitikerInnen auf die öffentliche Wahrnehmung von Person und Amt sowie des politischen Systems auswirkt.

Die Ergebnisse der wissenssoziologischen Diskursanalyse weisen darauf hin, dass Pathographien politischer Akteure stereotype Muster in der medialen Berichterstattung insbesondere über chronisch Kranke modifizieren. Zugleich zeigen die Befunde auf, wie PolitikerInnen Selbstthematizierungen ihrer Krankheiten instrumentalisieren, um Aufmerksamkeit in der Medienöffentlichkeit zu akkumulieren. In einem demokratietheoretisch wünschenswerten Sinne können so Verzerrungen im politischen Diskurs ausgeglichen werden. Problematisiert werden muss hingegen die Praxis, in Fremdthematizierungen politischen Konkurrenten stigmatisierte Krankheiten zuzuschreiben, um deren Position zu delegitimieren.

Matthias Bandtel hat an der Universität Mannheim Politische Wissenschaft, Medien- und Kommunikationswissenschaft und Philosophie studiert. 2009 Magisterexamen mit einer Arbeit zur visuellen Kommunikation des Vietnamkrieges. Seit 2010 wissenschaftlicher Mitarbeiter der Soziologie an der Bergischen Universität Wuppertal. Derzeit koordiniert er ein DFG-Forschungsprojekt zu *Politik und Komik* (Leitung: Andreas Dörner & Ludgera Vogt). Aktuelle Publikationen: *Aporien politischer Körper in der Mediendemokratie* (erscheint 2016), *Riskante Bühnen* (mit Andreas Dörner et al., 2015), *Die mediale Inszenierung von Pathologien politischer Akteure* (2014).

Workshop:

Strukturelle Traumanalyse: eine narrative Methode zur Analyse von Traumserien aus analytischen Psychotherapien

Deutsch/German

Prof. Dr. Christian Roesler

Klinische Psychologie
Katholische Hochschule Freiburg
Germany

Im Workshop wird die Forschungsmethode Strukturelle Traumanalyse (STA) vorgestellt und beschrieben. Sie erlaubt eine systematische Analyse der Bedeutung von Träumen in Analytischen Psychotherapien. STA versteht Träume als Narrative und greift auf narratologische Methoden zurück, um Hauptthemen und ihre Entwicklung im Laufe einer Psychotherapie zu identifizieren. Träume weisen auf die zentralen Probleme/Konflikte hin, aber enthalten auch Elemente, um diese Probleme zu lösen, und Traumserien folgen einer inneren Bedeutungsstruktur. Als Resultat können die Entwicklung der inneren Welt eines Patienten und die durch die Psychotherapie hervorgebrachten Veränderungen rekonstruiert werden, ohne dass man sich auf andere Information als auf die der Träume beziehen muss. Vergleiche der Resultate der STA mit den Berichten der behandelnden Therapeuten zur Psychodynamik der Patienten und dem Verlauf der Behandlung zeigen signifikante Parallelen. Die Methode wird gegenwärtig von Forschungsteams in den USA, Deutschland, der Schweiz und Japan eingesetzt.

Im Workshop wird die Methode beschrieben und anhand von Fallbeispielen erläutert.

Christian Roesler (*1967) ist Professor für Klinische Psychologie an der Katholischen Hochschule in Freiburg und Dozent für Analytische Psychologie an der Universität Basel. Er ist Jungianischer Psychoanalytiker in privater Praxis in Freiburg und Mitglied der Fakultät des C.G.Jung-Institutes in Stuttgart und Zürich. Er hat sich auf die Arbeit mit Paaren und Familien und auf interpretative Forschungsmethoden spezialisiert. Christian Roesler forscht und publiziert zu Analytischer Psychologie und zeitgenössischer Wissenschaft, Paarberatung, postmodernen Identitätskonstruktionen, narrativer Forschung und Medienpsychologie.

Session 2: Room SRB, Lecture Hall Building, 1st floor

Clinical realism- a new narrative genre and a potential tool to increase empathy in students

Paula McDonald

Senior Teaching Fellow
GP Sub Dean
Brighton and Sussex Medical School
Brighton
UK

English

The day to day experience of living with chronic health conditions is rarely represented in contemporary fiction. This workshop describes a narrative medicine and a creative writing course where medical students created a character with a chronic disorder and then wrote about them repeatedly over a period of four weeks, including details about the experience of living with the disorder. Analysis of the writing showed that the students created convincing and detailed narratives about living with chronic disorders, and introduced a number of themes relating to illness, including stigma, personal identity and narrative wreckage. Although some students reported that they initially felt little affinity for the characters they were allocated, their empathy for their character increased as they spent more time researching and writing about them.

This workshop will look at clinical realism, with an opportunity to try out some creative writing, but will also discuss how we can demonstrate outcomes of medical humanities interventions.

Paula McDonald trained in both Public Health Medicine and General Practice, and currently works as a GP in Brighton, UK, and as a Senior Teaching Fellow at Brighton and Sussex Medical School. Her workshop is based on a Narrative Medicine and Creative Writing module she previously taught at Manchester Medical School.

**What can we learn from patients' accounts of dementia?
Developing an educational module for dementia care in
intermediate vocational education in the Netherlands.**

Joyce Lamerichs, PhD

VU University Amsterdam
Faculty of Humanities
Department of Language and Communication
Amsterdam, The Netherlands

English

Manna Alma, PhD

University Medical Center Groningen,
Department of Health Sciences, Community and Occupational Health
Groningen, The Netherlands

Pupils in intermediate vocational education face many challenges when caring for demented patients and their families during their internships. Current educational materials prepare for this experience by using role play methodology to simulate communicating with patients with dementia (and their families). There is little opportunity to learn about patients' real needs in other ways. Supervisors in care homes observe that pupils are not at ease when caring for people with dementia and often seem afraid to 'make a connection' with patients.

Our contribution reports on a project that aims to develop a new educational programme for these pupils, on the basis of patients' accounts of their illness in over 80 narratives interviews available on the Dutch website pratenovergezondheid.nl.

We discuss the project's first results and report on some of the challenges we are facing in working with the different stakeholders.

Joyce Lamerichs is assistant professor at the Language & Communication Group at the VU University in Amsterdam. Her research is in the area of health communication and interaction, with a focus on language use in different health settings. How professionals talk with young people about health and illness is one of her areas of interest. She is currently working on a project about trauma talk with children.

Manna Alma is a post-doc researcher at the Department of Health Sciences, Community and Occupational Health at the University Medical Center Groningen.

Session 3: Room 2003 Main Building, 2nd floor

Workshop:

Experience as evidence for healthcare policy: a discussion about opportunities and challenges of using narratives to influence policy

Susan Law, MHSc, PhD

VP Academic, St. Mary's Hospital
Associate Professor, McGill Family Medicine
Montreal, Canada

Ilja Ormel, MPH

St. Mary's Research Centre,
Montreal, Canada

David Loutfi MSc

Doctoral Candidate,
Family Medicine, McGill University
Montreal, Canada

English

In this workshop, we will engage participants in a discussion about the potential value of narrative evidence in contributing to healthcare policy. Consideration will be given to the pragmatic limitations and challenges in this domain. Video clips will be presented from narrative interviews conducted in Canada on family caregiving and breast cancer as examples of participants speaking about problems that could be amenable to policy solutions. We will also outline the relevant policy context in Canada for these cases. In addition, we will highlight a few known examples from the UK where narratives from Healthtalk have influenced policy and clinical guidance. We will then draw on the expertise and experiences of the participants in the workshop (participants are asked to please bring examples from their countries of actual or aspirational cases of narratives used in policy) to contribute to a framework for thinking about these sorts of problems, strategies for policy influence, and likely challenges.

Susan Law (PhD) is Senior Manager at St. Mary's Hospital in Montreal, and an Associate Professor at McGill Family Medicine. She is the PI and founder of Healthtalk Canada and a board member for DIPEX International.

Ilja Ormel, (MPH) is Project Coordinator and lead qualitative researcher on the first 2 modules (caregiving and breast cancer) for Healthtalk Canada.

David Loutfi, (MSc) is a PhD student in family medicine at McGill University and research assistant working for Healthtalk Canada.

Session 3: Room 2003 Main Building, 2nd floor

When Public and Private Narratives Diverge: Experiences with Newborn Screening in the USA

Rachel Grob, MA, Ph.D

Director of National Initiatives

Senior Scientist, Associate Clinical Professor

Center for Patient Partnerships and Department of Family Medicine

University of Wisconsin-Madison

Prof. Mark Schlesinger

Professor of Public Health (Health Policy)

Yale School of Public Health

New Haven, USA

English

Newborn screening programs (NBS) have expanded in the United States “like a house on fire.” In public discourse, screening is cogently represented as saving lives. In private narratives, it is evident that experiences with screening are far more complicated: some lives are saved, but many more are *changed*. This session will explore the complex consequences for parents of receiving their child’s genetic diagnoses at birth, and contrast these narratives with public representations of patient voice. More specifically, how do NBS programs *feel* to parents who are most directly affected by them? What is the impact of early diagnosis on parenting practices, outlook for the future, and relationships with other family members and health professionals? How is NBS represented in the media, and by advocates pushing for additional expansion? What might account for the evident differences between the “private” voice of parents elicited in interviews and the “public” voice of groups purporting to represent parent’s collective interests?

Bios

Rachel Grob is Director of National Initiatives at UW-Madison’s Center for Patient Partnerships and Senior Scientist at the Department of Family Medicine. She is a sociologist whose career, both inside and outside academia, has been devoted to involving patients in the discourse, policy processes and institutional arrangements that impact their health care. Her research focuses include consumers’ experiences with newborn screening, advocacy, depression, prenatal care, primary care and low-value health care. She is the qualitative lead for DIPEX USA, and co-PI for the U.S.’s first.

Mark Schlesinger is Professor of Health Policy and a fellow of the Institution for Social and Policy Studies at Yale University. One theme of Dr. Schlesinger’s research focuses on how patients assess and make attributions about health care experiences, as well as how they respond to problems. He leads an initiative that explores the feasibility of incorporating elicited patient narratives into large-scale national surveys of patient experience and collaborates on the inaugural U.S. DIPEX module. His favored sports include uncompetitive volleyball and unlighted table tennis.

Survival Stories of Political Trauma. The Subjective Implications of Social Recognition: Empirical Psychosocial Study in Ecuador

Gina Donoso, PhD

Ph.D. Researcher

Department of Psychoanalysis and Clinical Consultancy,
Ghent University, Belgium

English

My study aims to analyze the subjective impacts that political violence has done to victims in Ecuador and the potential ways of recovery. It focusses on how social recognition to victims may help to produce new symbolizations to their experiences. From a psychoanalytical perspective, the presence or absence of social validation of the Other clearly influences trauma and recovery processes.

As part of my methodology, I conducted 7 focus groups during my field research in Ecuador. A group narrative methodology was chosen with the following objectives:

- Create a safe and place for participants in order that their story-sharing can be accompanied by peer support.
- Desindividualise an intrinsic political and social traumatic history.
- Encourage agency through a participatory data collection process.

Furthermore, researching trauma is not only an academic task, it is always a subjective encounter. The value of an ethical and committed researcher-participants bond when painful narratives are involved may produce a subjective recognition for victims which should have, at the same time, a positive restorative impact for political trauma survivors.

Gina Donoso is a Clinical Psychologist and a Ph.D. Researcher at the Department of Psychoanalysis and Clinical Consulting, Ghent University (Belgium). She is Consultant of the International Criminal Court and Justice Rapid Response and Regional Host for Latin America and the Caribbean of the Mental Health and Psychosocial Support Network. Her research and professional experience lie on the field of psychosocial recovery after trauma events. She has 12 years of international experience (Costa Rica, Colombia, Ecuador, Guatemala, DR Congo, Thailand, among others) working on programs of transitional justice and psychosocial support processes for victims and communities involved in political violence.

Workshop:

Pregnancy 2.0. A corpus-based case study for the analysis of illness narratives online

Eleonora Massa, PhD
Valentina Simeoni, PhD
Italy

English

Alongside its psycho-physical dimension, nowadays pregnancy is acquiring a particular relevance as a narrative theme on social networks: on Facebook, in particular, mother-to-bes follow specific, yet culturally and narratively shaped strategies for announcing, telling and sharing the whole process, thus experiencing it as a socially-mediated story.

After offering a theoretical frame to the issue of social networks as narrative tools, this workshop will engage the participants in the empirical analysis of a sample of pregnancy narratives taken from Facebook. How are they linguistically and rhetorically constructed? Which relational and socio-pragmatic features do they let emerge? What idea of “pregnancy” do they convey?

These and other questions will support the analysis and lead to a final discussion regarding the cues that online narratives can offer to the medical staff to interpret their patients’ experience of pregnancy.

Eleonora Massa was born in Rome (Italy) in 1983. She holds a bachelor’s degree in German and English Language and Literature (2006) and a master’s degree in Translation Studies (2009). She obtained her Ph.D. in General Linguistics in 2013 with a dissertation on narrativity as a theoretical and methodological approach to the didactics of foreign languages. She currently works as a foreign language teacher and an independent researcher: her main interests focus on the processes of language acquisition and use as narrative practices. Together with the co-author of this workshop she has recently published “Once upon a tale. On the foundational role of narrative in constructing linguistic and social experience” (*Journal of Comparative Research in Sociology and Anthropology*, 2014).

Valentina Simeoni was born in Castelfranco Veneto (Italy) in 1983. She graduated in Philosophy (Padua, 2005) and then in Anthropology, Ethnology and Ethnolinguistics (Venice, 2009). She later obtained her Ph.D in Anthropology and Epistemology of Complexity (Bergamo, 2012) with a dissertation on the traditional narratives of Georgian highlanders in relation to their sacred geography. She currently works as a language teacher, a translator and an independent researcher with a specific interest in storytelling as a linguistic and social practice. She has recently published, among others, “Once upon a tale. On the foundational role of narrative in constructing linguistic and social experience” (*Journal of Comparative Research in Sociology and Anthropology*, 2014).

Are DIPEX narratives truly "useful" for patients? —Analyses of 'thank you!' buttons and short comments in DIPEX-Japan website

Akiko Sawada

DIPEX-Japan,
Health Care Center, Iwaki Meisei University

Yoko Setoyama

DIPEXJapan
Department of Nursing, School of Medicine, Tokyo Medical University

Rika Sakuma Sato

DIPEXJapan

English

We explored users' reactions to the video narratives in the DIPEX-Japan website by analyzing the data of social monitoring tools, 'thank you!' buttons and 'short comment' textboxes installed in every narrative clips.

In this study, one-year data in 2014 from breast cancer and prostate cancer modules were analyzed. Google Analytics was also used to calculate the Number of page views Needed to get one click on the 'Thank you!' button (=NNT).

We found that clips in topics with practical information tended to get more 'thank you!' However, topics regarding personal relationships and philosophical issues around life and death got lower NNT than those topics.

The content analysis of short comments revealed that a large majority of comments from patients were expressions of empathy for those with similar conditions. While families and healthcare providers often commented that they learned something 'new' from the narratives, patients tended to value narratives that reaffirmed their feelings and decisions.

Akiko Sawada is a member of the DIPEX-Japan and a main researcher of prostate cancer module. She graduated from University of Tsukuba, Graduate School of Comprehensive Human Sciences with a master's degree in human care sciences.

Her main interests include clinical psychology. She works in Iwaki Meisei University as a full-time counselor in student counseling room.

Yoko Setoyama and **Rika Sakuma Sato** are both members of DIPEX Japan.

Epistemological Shifts in the Re-Analysis of Diabetes Narratives: Swinging between Narrative Inquiry and Grounded Theory

Heewon Chang, PhD
Eal Whan Park, MD, PhD
Eun-Mi Hwang, PhD
Korea

English

This methodological article discusses the epistemological shifts that the co-researchers have experienced in the process of re-analyzing existing illness narratives to construct a grounded theory of effective diabetic patient management. Initially the co-researchers espoused the epistemology of the narrative inquiry in which patients' unique experiences were regarded as valued knowledge from the emic perspective. However, in order to construct a theory, the co-researchers had to shift their view of the narratives as a source of knowledge that can be standardized, compared, and evaluated from an etic point of view. They constructed an evaluative rubric grounded on the narratives. When utilizing the evaluative rubric, the researchers felt a challenge to fit unique narrative details into a generalizable theory. Despite the challenge, the methodological and epistemological shift from narratives to grounded theory back to narratives enabled the co-researchers to gain a practical and transferrable knowledge from existing illness narratives.

Heewon Chang, PhD, is a professor of education and organizational leadership at Eastern University in the United States. She teaches doctoral courses and conducts research in qualitative research, multicultural education, and organizational leadership. She has published four books including *Autoethnography as Method* (2008) and *Collaborative Autoethnography* (2013) and book chapters and articles in her research areas. She has founded two open-access scholarly journals focusing on multicultural education and is currently serving the *International Journal of Multicultural Education* (www.ijme-journal.org) as Editor-in-Chief.

Eal Whan Park, MD, PhD, is a professor of family medicine at the College of Medicine at Dankook University in Korea. As a co-researcher of the DIPEX-Korea research team, he participated in developing the database of patients' illness narratives in Korea. He is a board member of DIPEX international and represents DIPEX-Korea. His research interest includes doctor-patient relationship in chronic illness, patient and family empowerment in primary health care, and narrative approach to substance abuse patients.

Eun-Mi Hwang, PhD, received her doctoral degree in German linguistics from Ruhr-Universität Bochum in Germany in 2003. Her dissertation is titled *The Study of Phraseology in the Equestrian Sports Language (Empirische Untersuchungen zur Phraseologie in der deutschen Pferdesportsprache)*. She is a lecturer affiliated with the Institute of Core Education at Seoul National University in Seoul, Korea. Her research focuses on communication.

Session 5: Room 5003 Main Building, 5th floor

Enabling Techniques: How to touch an experience

Iva Poláčková Šolcová, PhD

Institute of Psychology, Czech Academy of Sciences
Olomouc Social Health Institute (OUSHI), Czech Republic

English

Prof. Peter Tavel

Olomouc Social Health Institute (OUSHI), Czech Republic

Co-authors: Eva Dubovská, Kateřina Hamplová, Lucie Klůzová Kračmárová, Zuzana Půžová, Olomouc Social Health Institute (OUSHI), Czech Republic

Enabling techniques (ET) are used in qualitative research, particularly within in-depth interviews, to enable a participant express their views and experiences in an articulate way. ET facilitate to construct a problem „differently“ in response to a question and allow to a participant to see and say „more“ about their less conscious, less rational, less socially-acceptable experiences, emotions, beliefs or motives. ET serve to depersonalize the discussion by moving away from direct questions and instead enable participants to re-construct their feelings, beliefs, attitudes by describing (see through) visual stimuli, representations, completing thought bubbles, selecting from a stack of photographs the picture etc. ET allow to detect participants' implicit beliefs, stereotypes, and myth that have influenced their behaviour, experience or decision. In qualitative health research we use many ET; in our presentation we will show the most useful of them - word association, metaphorical projections (analogy, animation, personification, and metamorphosis) and others.

Iva Polackova Solcova received her Ph.D. in the Social Psychology from Charles University in Prague. In 2011 she joined Institute of Psychology in the Czech Academy of Science where she focused on affective processes in the realm of Space Psychology (simulated fly to Mars). In 2014 as a postdoc research scientist she started to examine the process of affective habituation experimentally. From 2013 she is an assistant professor at Faculty of Humanities (Charles University in Prague) where she teaches psychology and qualitative research. She is a member of Olomouc Social Health Institute (OUSHI) and DIPEX team CR.

Peter Tavel is a professor of clinical psychology and a dean of Faculty of Theology at Palacky University Olomouc. He works with palliative patients and supervises work of mobile hospice. His rich research interests range from the psycho-spiritual determinants of health to research of lived experiences of elderly people and qualitative research of health and illness. Peter is also external member of research team at Groningen University, Netherlands and is a founder and leader of OUSHI and DIPEX team in CR.

Eva Dubovska is a psychologist and researcher. She graduated from Prague College of Psychosocial Studies, and currently studying Ph.D. at Department of Psychology of Palacky University Olomouc. Her main research interests are qualitative research of psychotherapy and mental health and DIPEX.

Katerina Hamplova graduated in Social Work with Focus on Counselling at Ostrava University in Ostrava. During her studies she taught English and studied graphology. After graduation, she worked as a social worker at the Department of social and legal protection of children, where she was in charge of the agenda of foster and adoptive care. Currently she works in Olomouc Social Health Institute (OUSHI) as junior project manager.

Lucie Kluzova Kracmarova is a psychologist and researcher. She graduated from Palacky University, Olomouc, Czech Republic. Currently she is a Ph.D. candidate in clinical psychology at the Department of Psychology at the same university. She works as a

researcher for the Czech DIPEX team (active ageing module) in Olomouc Social Health Institute (OUSHI). Beside DIPEX she is interested in research of dreams and nightmares, and psychosomatics.

Zuzana Puzova graduated at Palacky University Olomouc in active lifestyle management and marketing. Within her studies at Palacky University she studied at University of Jyväskylä, Faculty of Sport and Health Sciences, specifically Sport & Marketing, Organisation and role of sport in the EU and its member states. Currently she is studying her Ph.D. in kinanthropology at Palacky University Olomouc. She works in Olomouc Social Health Institute (OUSHI) as an economic and administrative manager. She is also a financial manager of the HBSC study in the Czech Republic. For a few years she has been working as a project manager of grant schemes in science and development on national (CSF, ESF) and international level (DG EAHC, DG SANCO, EU Leonardo).

Session 5: Room 5003 Main Building, 5th floor

Autonetography: A Methodology at the Heart of Things

Dr. Joshua Prenosil
Creighton University
Omaha, NE
USA

English

This presenter will use a case study of medical advocacy to develop a methodology to complement Bruno Latour's actor-network theory (ANT). Specifically, the presenter will provide a patient account of illness and recovery from cardiac laminopathy, a rare genetic disease with no cure and limited treatment options. The presenter in this case is also the patient, one whose personal experience of illness, recovery, and advocacy is relevant to the analysis at hand. Yet, as the presenter will show, conventional actor-network theory does not legitimate personal narrative in its methodology. Consequently, the presenter will propose a new methodology, autonetography, as an autoethnographic complement to ANT. Finally, the presenter will conclude by outlining methods for maintaining the scope of conventional actor-network scholarship while integrating patient narratives, which cross genres, institutions, and disciplines.

Joshua D. Prenosil is an assistant professor of English at Creighton University in Omaha, NE, where he teaches courses in rhetorical theory, professional writing, composition, and multimedia production. Dr. Prenosil's research happens at the intersections of rhetoric, philosophy, and sociology, and he is especially interested in contemporary material-semiotic theory. Per his kindly demeanor and love of napping, his students have nicknamed him "Old Man Prenosil." And, true to form, on weekends Dr. Prenosil can be found at antique/thrift shops and estate sales uncovering hidden treasures.

“You can never be the same again”: Identity re-construction following an Acquired Brain Injury. A case study.

Chalotte Glintborg

Department of Communication and Psychology
Aalborg University
Denmark

English

The transition from being well and fully functioning to being suddenly disabled by an acquired brain injury (ABI) and having to start a recovery process has a huge impact on a person's life and, presumably, identity. However, research is still sparse on the psychosocial consequences following ABI, and there is a lack in identity research based on interviews with clients, i.e., how clients themselves construct their situations, and recovery processes following ABI.

A case study will be presented based on a female adult with ABI aged 27 years who was interviewed twice –during hospitalization and one year post injury in her personal home (using semi structured interviews). Discourse analysis drawing on the concepts of positioning and agency was applied to investigate participants' (re)constructions of identity through self-narratives. The results will be discussed in light of the possible benefits of focussing on narratives in practice

Chalotte Glintborg is a Ph.D. fellow in psychology at Aalborg University, Denmark. Her research interest includes the psychosocial consequences of an acquired brain injury, illness narratives, identity (re)construction, psychological rehabilitation and rehabilitation programs based on the bio-psycho-social model. Her most recent paper publication is: Glintborg & Krogh (2015). The power of narrative: identity reconstruction following an acquired brain injury. A case study. *Globe, A Journal on Language, Communications and Culture*, 1, 93-106. E-mail: cgl@hum.aau.dk

To take or not to take? Online discussion of adolescents with ADHD regarding compliance with medication treatment and medication effects on their personality

Erez C. Miller, Ph.D

Achva Academic College, Israel

Amos Fleiscmann, Ph.D

Achva Academic College

English

The use of medication to treat children and adolescents with ADHD has grown markedly. Learning about medication compliance is important for clinical practice and for studying long-term treatment outcomes, especially considering the high developmental risk of untreated ADHD.

The present study investigated the decision making processes of youths with ADHD in online ADHD teen forums, regarding pharmacotherapeutics use and its effects.

Research Question: What do adolescents with ADHD share among themselves regarding pharmacotherapeutics use and their effects on their personality, as reflected in online ADHD teen forums?

Data and methods: Online forums conversations among adolescents with ADHD were collected during one year. Only those conversations that focused on medication use were collected and analyzed, using discourse analysis.

Results: Adolescents with ADHD shared a number of causes for noncompliance with medication treatment, especially ineffectiveness and side effects, including impact on their personality and mood.

Erez C. Miller is a senior lecturer at Achva Academic College. He was the co-developer of the new B.Ed. teacher training program in Special Education at Hemdat Hadarom college, and the M.Ed program in Special Education at Achva Academic College. He graduated with Ph.D in Dev. & Ed. Psychology from Boston College. Dr. Miller teaches courses and conducts research projects in the fields of special education, people with disabilities, and online narratives of individuals with disabilities. Dr. Miller is a practicing licensed psychologist, specializing CBT with of children and adolescents.

Development of New Educational Program Using Patients' Narratives in DIPEX-Japan

English

Prof. Natsumi Morita, PhD, RN
Department of Nursing
School of Health Sciences,
Tokyo University of Technology, Japan

Co-authors:

Noriko Iba, Hirokuni Beppu, Yuko Hirono, Rumiko Akimoto, Chikako Nakamura, Keiko Goto, Emiko Wada, Yoko Setoyama, Mikiyo Sato, Akiko Aoki, Miyuki Semba, Natsuko Takahashi, Tomoko Arahata, Tomiko Takeuchi, Akiko Sawada, Rika Sakuma Sato, Kunihiro Kumamoto, Takeo Nakayama,
Team DIPEXJapan

All healthcare professionals' need is listening to the patient's narrative genuinely, approaching the patient's problem holistically. Making efforts to achieve this goal will provide a deeper insight into human nature. We are developing the educational program using DIPEX-Japan database which is for healthcare professionals to improve their understanding of patients and illness as a whole person.

We have invited teachers in the fields of healthcare education to use patients' narratives in our database. Although many teachers have come to use the short video clips from our website, we have noticed that there is a limitation. To achieve the goal mentioned above, we have selected an interview with one breast cancer patient and edited a 20-minute-long video, and developed an educational program.

We report the process of developing the program and our trial of using this program in the class of nursing students.

Natsumi Morita is professor at the Department of Nursing, School of Health Sciences, Tokyo University of Technology, Japan. Her main interests and research activities are "*kimochi*", or the world of experience, in patients living with hemodialysis of end-stage renal disease, and to develop the educational/training program for nurses working in hemodialysis unit to come to understand patients empathetically. Her research and living philosophy is based on Person Center Approach (PCA) by Carl Roger. Her publications include *Kimochi: Capturing Elderly Japanese Dialysis Patients' Experiences*, In: *Faces of Aging: The Lived Experiences of The Elderly in Japan*, Ed. Yoshiko Matsumoto, p.170-193 (Stanford University Press, 2011), and "*Ketsueki Toseki ryoho o ukete seikatsu suru mansei jinfuzen kanja no "kimochi" no kozo*" (The structure of *kimochi* in patients living with hemodialysis of end-stage renal disease), *Journal of St. Luke's Society for Nursing Research* 12(2), 2-13 (2008). Her **co-authors** are all part of the DIPEXJapan team. ,

**Teaching of patients' experiences: the website
www.krankheitserfahrungen.de**

English

Alexander Palant
Institut für Allgemeinmedizin
Universitätsmedizin Göttingen
Germany

To understand patient's perspective is an important component in medical education. However, today most of the patient presentations during the training focus on the illness, rather than on the people themselves. Illness narratives illustrate physical, social and emotional experiences of the patients and can help medical student to get a better understanding of sometimes difficult situations, which some of their patients can encounter. Such illness narrative can be found on the German version of the British DIPEX website under the link www.krankheitserfahrungen.de. Furthermore, those interview fragments are very well suited for being used in medical education. Therefore the author developed a concept to raise awareness for patient's perspective by showing several videos and giving the medical students some exercises after the presentation. This way it is maybe possible to improve communicative skills for a better patient-doctor-relationship.

Alexander Palant was born in Ukraine and moved to Germany as a teenager. After finishing school he studied social sciences at the Georg-August-University in Göttingen. After his diploma he completed the training as an intercultural Trainer before accepting a position in 2011 as junior research fellow at the Institute of General Practice, University Medical Center Göttingen. During his studies and till 2013 he was a tutor for communication training for medical students. Currently he is writing his PhD Thesis about people with inflammatory bowel diseases.

Session 6: Room 2005 Main Building, 2nd floor

**Workshop:
Shared Encounters, Individual Narratives: Writing About Clinical
Experiences**

English

Christine Montross MD, MFA

Assistant Professor of Psychiatry and Human Behavior
Brown University, Rhode Island, U.S.A.

In this session, psychiatrist and author Dr. Christine Montross will use clinical anecdotes from her most recent book, *Falling Into the Fire: A Psychiatrist's Encounters with the Mind in Crisis*, to launch broader discussions about employing narrative to examine the challenges implicit in caring for the very ill. The workshop will be conducted in the style of a literary salon. Dr. Montross will begin by sharing two brief excerpts from her own work. She will then lead the group in a series of writing prompts, inviting participants to write their own fragments of health narratives, drawing from some of the more evocative moments in their own clinical experiences. The workshop will finish with a discussion of the process of engaging in the creation of health narratives, as well as an exploration of the content which has emerged therein.

A 2015 Guggenheim Fellow in Nonfiction, **Christine Montross** is Assistant Professor of Psychiatry at Brown University. She is also a practicing inpatient psychiatrist. Prior to attending medical school she received a Master of Fine Arts in poetry from the University of Michigan. Dr. Montross's first book, *Body of Work*, was named an Editors' Choice by *The New York Times* and one of *The Washington Post's* best nonfiction books of 2007. Her second book, *Falling Into the Fire*, was named a *New Yorker* Book to Watch Out For.

Session 7: Room 3005 Main Building 3rd Floor

Methodologische und ethische Herausforderungen in der qualitativen Sozialforschung mit demenzerkrankten Menschen

Aisha-Nusrat Ahmad

Fachbereich Gesellschaftswissenschaften
Goethe-Universität Frankfurt
Germany

Prof. Phil Langer

Fachbereich Gesellschaftswissenschaften
Goethe-Universität Frankfurt
Germany

Deutsch/German

Forschung mit an Demenz erkrankten Menschen stellt eine method(olog)ische und forschungsethische Herausforderung dar. In der Tradition partizipativer Forschung wurden in der Studie "50plusHIV" HIV-infizierte Menschen mit Demenzerkrankungen nach ihren Erfahrungen des Älterwerdens mit der Erkrankung befragt. In Anbetracht der besonderen Situation von Demenzerkrankten wurden die im Rahmen eines qualitativen Studiendesign entwickelten Methoden dafür modifiziert. In der Paper-Präsentation sollen die Erfahrungen und Herausforderungen durch die Beteiligung von demenzerkrankten älteren HIV-positiven Menschen im Forschungsprojekt hinsichtlich der Datenerhebung während des Interviews und in den ethnographischen Fallstudien, der Datenanalyse und Ergebnisdarstellung vorgestellt und die Forschungsentscheidungen, die dabei getroffen wurden, kritisch reflektiert und diskutiert werden.

Aisha-N. Ahmad ist wissenschaftliche Mitarbeiterin am Fachbereich Gesellschaftswissenschaften der Goethe-Universität Frankfurt. Sie promoviert zu den Lebenssituationen älterer HIV-positiver Migrant*innen.

Phil C. Langer ist Juniorprofessor für Soziologie und Sozialpsychologie am Fachbereich Gesellschaftswissenschaften der Goethe-Universität Frankfurt. Er arbeitet derzeit u.a. an psychosozialen Aspekten des Älterwerdens mit HIV und Aids sowie den Folgen der Erfahrungen kollektiver Gewalt bei Jugendlichen in Afghanistan.

Narrative in der Ärzte Weiterbildung in Korea

Prof. Yon-Ok Jung
Pflegerwissenschaft,
Universität Kyungdong
Korea

Deutsch/German

Prof. Yong-Ik Bak
Germanistik
Universität Korea
Seoul, Korea

In dem Vortrag soll die Verwendung von Narrativen in der koreanischen Ärzte Weiterbildung vorgestellt und besprochen werden. Dabei wollen wir auf die konkreten Inhalte und Methoden der Verwendung von Narrativen etwas genauer eingehen. Die einzelnen Themen, die wir in dem Vortrag behandeln wollen, sind wie folgt:

- ✓ Eine kurze Einführung in die koreanische Medizin und medizinische Ausbildung
- ✓ Medizinische Kommunikation in der koreanischen Medizin und die Rolle der Narrative
- ✓ Narrative und die konfuzianistisch geprägte koreanische Gesellschaft
- ✓ Verwendungsmethoden der Narrative für die Ärzte Weiterbildung: Narratives Interview und Textanalyse von Patientenerzählungen
- ✓ Erfahrungen mit der Verwendung der Narrative (Erfolge und Konflikte)

Yonok Jung ist Professorin für die Pflegerwissenschaft an der Universität Kyungdong in Gosung. Sie promovierte 2014 über Kommunikationserfahrungen von Pflegerinnen im Fach Pflegerwissenschaft an der Universität Kyunghee in Seoul. Ihre Hauptforschungsgebiete sind qualitative Forschung und Pflegekommunikation.

Yong Ik Bak, Forschungsprofessor im German Studies Institute an der Korea Universität in Seoul, promovierte 1993 über die Dialoganalyse von bilingualen Unterrichtsgesprächen im Fach Allgemeine Sprachwissenschaft an der Universität Münster. Seine Hauptforschungsgebiete sind Dialoganalyse, linguistische und qualitative Erzählforschung und medizinische Kommunikation. Neben universitären Lehr- und Forschungstätigkeiten lehrt er auch medizinische Kommunikation und narrative Medizin für Mediziner und Pflegerinnen.

Workshop:

Kranksein in der Arbeitswelt – Krankheitsnarrationen und biografische Entscheidungen bei der Rückkehr in die Arbeitswelt nach beruflichen Qualifizierungsmaßnahmen

Prof. Ernst von Kardorff

Institut für Rehabilitationswissenschaften
Humboldt-Universität
Berlin, Germany

Alexander Meschnig

Sebastian Klaus

Deutsch/German

In den meisten Krankheitserzählungen erscheint die Arbeitswelt – wenn überhaupt – nur in der Perspektive als (Mit-)Verursacher der Krankheit. Nach einer Rückkehr an den Arbeitsplatz nach Rehabilitationsmaßnahmen, werden noch verbliebene gesundheitliche Beeinträchtigungen, Schmerzen oder Stress am Arbeitsplatz nur auf gezielte Nachfrage thematisiert; hierbei zeigen sich gesundheitsstabilisierende wie -gefährdende narrative Konstruktionen des Arbeitens mit und trotz chronischer Beschwerden, die wir anhand kontrastierender Erzählungen analysieren.

Ernst von Kardorff, Institut für Rehabilitationswissenschaften der Humboldt-Universität zu Berlin; Arbeitsschwerpunkte: Analyse des Lebens mit Behinderung und chronischer Krankheit, Berufliche Wiedereingliederung und Return to work, Stigmatisierungsprozesse, Soziale Unterstützungsnetzwerke sowie qualitative Forschung in der Rehabilitation.

Session 8: Conference Room Main Building 6th floor

Illness narrative or narrative of social injustice can we listen to a different story?

Dr. Maya Lavie-Ajayi
Social Work Department,
Ben Gurion University of the Negev
Israel

English

This paper discusses the difficulties of therapists to hear a story about social injustice when they expect a story of emotional difficulties. It includes an analysis of a single intake session taken from a large study on mental health intakes in safety-net mental health clinics in Israel with culturally diverse populations. The client self-presented herself as being in a state of crisis as a result of deterioration in her employment status which she attributed to systematic corporate injustice. The therapist was a senior clinician. During the intake there were a number of disagreements between the client and the therapist: while the client was trying to tell a narrative of injustice the therapist insisted on hearing an illness narrative. The paper brings forward the argument of the client, who perceived the battle of narratives as a political battle and highlighted the political power of psychologists to define diagnosis and treatment recommendations.

Maya Lavie-Ajayi is a health psychologist. She works as a lecturer in the Department of Social Work and as academic coordinator of the Israeli Centre for the Qualitative Research of People and Society at Work at Ben Gurion University of the Negev, Israel. Her research interests include inequalities in mental and general health services, experiences of health and illness, discourses of sexual health and sexuality and feminist research methodology.

Session 8: Conference Room Main Building 6th floor

How to think when you are not able to think, how to describe something not existing, how to speak with the other who screams? Challenges of research and diagnostic interviews on pain

Weronika Kalwak MA
Jagiellonian University
Cracow, Poland

English

It is claimed that adequate pain diagnosis is necessary for effective pain management. On the other hand, subjective and private nature of pain together with epistemological exclusiveness and authority of a pain sufferer hinder standard scientific investigation with the use of objective, third-person perspective methods of diagnosis and measurement, whereas first-person perspective methods of studying subjective pain experience are broadly used and accepted. Various quantitative self-report tools used to measure pain intensity and characteristics with established reliability and accuracy reputed to be the gold standard in pain diagnosis. Thoroughly recognised difficulties of employing them into medical practice justify to some extent recent increases of engaging in pain studies qualitative methods described as a source of valuable, deeply contextualised and practically applicable knowledge. The aim of presentation is to discuss challenges of qualitative interviewing about pain applicable to research and medical diagnostic dialogue between the patient and the medical professional.

Weronika Kalwak received a MA degree in psychology in 2011 and MA in philosophy in 2014 at Jagiellonian University in Cracow, Poland. At the moment at Health Psychology Department (Institute of Psychology, Jagiellonian University) she is completing her PhD thesis which is an interdisciplinary attempt to describe and understand a biopsychosocial phenomenon of pain diagnosis with its medical, cognitive, existential and interpersonal dimensions. Her academic interests consist of qualitative methodology, phenomenology in cognitive science and health psychology.

Session 8: Conference Room Main Building 6th floor

Workshop: Designing for Chronic Pain - Exploring the intercorporeal

Chris Heape

Design Research Consultant

Preben Friis

Theatre Lab

Prof. Henry Larsen

Professor of Participatory Innovation

Sanne Grangaard

Actress and consultant

English

SDU Design Research,
University of Southern Denmark,
Kolding, Denmark.

The basis for our proposed workshop is an ongoing research project, initiated to explore if and how design inquiry with its processes, methods, tools and interventions can contribute to chronic pain care and research. Our findings over the past year have revealed that for those in pain, it is not so much a question of being better able to perceive and express pain, as was originally assumed, as it is an ability to perceive, make sense of and express a changed life situation and the effect this has on relations with others. Chronic pain weaves its way into the very fabric of people's daily lives, both at work and at home. By this we mean family, friends, colleagues, the work place, health carers and all manner of public sector workers who, in some form or other, have to engage and relate to a person with chronic pain and vice versa.

Chris Heape is part of the Design Anthropology group at SDU Design and his research interests are centred around design process, design education and design anthropology. The Pain Care project represents a departure into social design.

Preben Friis uses insights, practical knowledge and skills from theatre to work with student education and as a way of informing alternative research processes. The Pain Care project is one of such research projects where theatre methods play a role.

Henry Larsen is interested in processes of social negotiation and how meaning and action is co-created in such interactions, including themes that are usually perceived as individual such as pain.

Sanne Grangaard works in collaboration with SDU Design Research. She is the owner of Teatret Grangaard Consult and also works in collaboration with Dacapo A/S Odense Denmark.