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Birthe Loa Knizek
Sven Hroar Klempe *Editors*

Foundation of Ethics-Based Practices

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About the Editors and Contributors

About the Editors

Birthe Loa Knizek was raised bilingual in the Danish minority in Germany, where she developed a life-long interest in and awareness of cultural and linguistic differences and what they mean to people. She was awarded the titles mag.art. psych. and PhD from the Psychology Department, Center for Qualitative Methods, Aarhus University, Denmark. Her background includes assoc.prof., CEKVINA (Center for Womens' Studies in Aarhus), Aarhus University, Denmark; assoc.prof., leader of the long distance education in psychology, Ålborg Universitetscenter, Denmark; assoc. prof. in Theory of Science Problems in Psychology and Qualitative Methods, Department of Psychology, The Norwegian University of Science and Technology (NTNU), Trondheim; full professor in Community Psychology, Norwegian University of Science and Technology; full professor in Mental Health, Sør-Trøndelag University College, Norway; and full professor, Mental Health, Norwegian University of Science and Technology, NTNU. Her research ranges from German psychosomatics, which emphasized the influence of personal experiences for the formation and health of the body, based on Uexküll's theories, over suicidal behaviour and suicide prevention in Norway, Ghana and Uganda focusing on cultural complexity and the decisive importance of individuals' context, to mental health among children and adolescents living with HIV/AIDS in Uganda. Alongside she has an interest in morality and ethics guiding (global) mental health efforts. From 2016 to 2020 she was leading the multinational researcher network "Health in Context" with the focus on meaning-making and health. In addition, she is a specialist in Clinical Psychology (Children and Adolescents) with numerous years of clinical practice. For more information on publications: https://innsida.ntnu.no/my-profile.

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Tor-Johan Ekeland is Professor of social psychology at the Faculty of Social Science and History at Volda University College and Professor II at Molde University College. He has previously held positions at Nordic University of Public Health, Gothenburg; and University of Bergen. Recently, his research has addressed the interplay between epistemology, neoliberal governing and practice in the mental health field, and he has published both empirical and theoretical studies on these themes. Ekeland has also clinical experience.

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Maria Francesca Freda PhD is full professor of Clinical Psychology in the Department of Humanities at University Federico II of Naples, Italy. She teaches methodology of clinical intervention and is head of the Narrative lab at the master's degree in Clinical Psychology. She is head of the services for the undergraduates' psychological support of the University Center for the active and participated undergraduates' inclusion (SInAPSI). Her main research interests relate to the role of narratives in the elaboration of critical events from a semiotic and constructivist perspective, to the sensemaking process of chronic diseases' experience, and to University engagement. She is the author of several national and international books and articles on such themes.

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Chapter 1
Overview of the Volume

Birthe Loa Knizek

This special issue of theoretical annals in psychology is focusing on ethics-based practice. ‘Ethics-based practice’ contrasts in many ways ‘evidence-based practice’, which has the following definition: ‘Evidence-based practice in psychology (EBPP) is the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences’ (APA, 2006, p. 273). According to the American Psychological Association, there is broad consensus that psychological practice needs to be based on evidence and that psychology ‘… is distinctive in combining scientific commitment with an emphasis on human relationships and individual differences’ (ibid, p. 274). Furthermore, the authors from APA underline psychology’s possibility to develop, broaden and improve the evidence base. Clinical expertise is here important as we here find the psychologists’ latitude in adjusting generalized knowledge to the needs of a particular patient and consider the patient and his or her family’s worldview and sociocultural context (ibid, p.276). From the outset, patient values and preferences were regarded a central component of evidence-based practice and was meant ‘…to enhance the delivery of services to patients within an atmosphere of mutual respect, open communication, and collaboration among all stakeholders, including practitioners, researchers, patients, health care managers, and policymakers’ (ibid, p. 280).

From the original definitions and descriptions, evidence-based practice seems sincerely concerned with the particular patient and calls for flexibility and adjustment, and seen from a communicational perspective, ‘evidence’ as a basis for clinical practices has been a great success. Thus, the term is applied and appears in all aspects of clinical health and social work. It has become a kind of slogan that signalizes proper values and scientific guidelines for each field and subject. However, initial good intentions and reality not always harmonize, and political

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guidelines and instructions can thwart the original intentions and ethical problems arise. Standardized procedures and manuals seem to limit the flexibility in the encounter between psychologists and their clients, which consequently influences the basis of their encounter. We see an increasing slide from the original recognition of individual needs to a fundamental assumption of a universal human, where one size fits all. This ontological slide has epistemological consequences giving guidelines for what is counted as correct knowledge that practice should be based on. The consequential problems are the focus of this special issue of Theoretical annals of Psychology, where different consequences of evidence-based practise are discussed and the need for ethics-based practise demonstrated. As the arguments for changing evidence-based to ethics-based can be many and this compilation aims at bringing in as broad perspectives as possible.

The first two chapters by Sven Hroar Klempe and Tor-Johan Ekeland lay the ground for all following chapters. Klempe looks at the general premisses by following up the association between science and logic and problematizes this link as the current scientific discourse has a problem with accounting for the gap between knowledge acquired from thinking on the one hand and knowledge acquired from experiences on the other. In his chapter, Klempe investigates how this fundamental gap can be filled and he questions the relationship between science and logic and takes a closer look at the linguistic turn, where he concludes that the use of language is entrenched in interests, which form a considerable part of the gap between thoughts and experiences. He suggests that an ethics-based logic of science must reveal the content of this gap by means of maximized honesty.

Tor-Johan Ekeland's chapter is the prominent chapter in this volume that makes up the point of reference for all the following chapters as he elucidates the implicit moral claims in evidence-based practice. He opposes the fundamental idea of defining what can be regarded as legitimate knowledge resulting in best practice. In his convincing argument, he discusses the evidence-based practice's epistemological claims and their consequences for 'best practice' and based on historical examples demonstrates that evidence-based practise's epistemology is no guarantee for an ethical practice as it sometimes even might increase inhumanity. From Ekeland's strong arguments laying the foundation for the critical look at evidence-based practices and the need for reinstalment of ethics as the basis for practice the following chapters target specific problematic aspects of normative evidence-based procedures and explore alternatives.

From evidence-based practices' ontological assumptions and epistemological claims, we take a look on ethical challenges in methods that might follow in the wake. John-Arne Skolbekken's outset is type 2 diabetes, which currently is presented as a global health challenge of epidemic proportions. Identification of high-risk individuals has become an essential part of a strategy to meet this challenge. During this identification process within a risk discourse, individuals are offered new subject positions, attributed with personal responsibility for maintaining their own health as many health risks are defined as the outcome of individual lifestyle choices. The individuals thus are burdened with a lifelong diagnosis and maybe without ever experiencing a symptomatic disease. Shame and blame might follow the diagnosis, while structural injustice and poverty seem overlooked.

In the next chapter, Katrina Jaworski focuses on ethics beyond the practical concerns of university human research ethics committees. She employs her experiences of interviewing queer young people about their familiarity with suicide in an unstructured interview technique. Inspired by the work of Judith Butler, Emmanuel Levinas, Michel Foucault and Donald W. Winnicott, she demonstrates that research ethics in the process of unstructured interviewing are about ontology as much as about practical issues and that researchers and the researched equally are implicated in the relationship between research ethics and ontology.

From ethical challenges in methods, the focus shifts to ethical challenges in therapy, where Stordahl and colleagues have asked 51 clinical psychologists in a net-based survey one question regarding their first thoughts after meeting a new client. The respondents in the study tended to prioritize morally charged concepts, which draws attention to psychological practices implicitly that are based on ethics. The existential dimension of therapy seems central in their work with specific patients and based on experiences from important psychological encounters with that person as well as earlier experiences as therapists.

Daniele Bruzzone follows up the existential dimension in his chapter, where he reminds us that both patients and caregivers are facing radical questions about the meaningfulness of life when facing illness. In crises situations, Viktor Frankl's meaning-oriented psychotherapy represents an attempt to restore the inner spiritual resources of a person and turn limit-situations into challenges and opportunities for personal growth. His prime example of logotherapy's application in clinical contexts is meaning-centred group therapy conducted with cancer patients; clinical experience and research proves that investing in meaning and values acts as a psychological protective factor and a therapeutic resource in coping with illness.

From adults, the focus is changed to children with parents suffering from mental disorders and/or drug abuse in the chapter by Birgit Nordtug and Cathrine Grimsgaard. They focus on how one can meet children's basic human need for care and their desire to be taken seriously as meaning-making subjects. Based on Lacan, Gadamer and Heidegger, they explore the possibility of establishing an ethics-based practice by means of narratives about different interactive situations in seven conversation groups for children with parents suffering from mental disorders and/or drug abuse issues.

From a clinical perspective on health psychology, Picione, Freda and Savarese consider health as a multidimensional process generated from the connection between several experiential trajectories: bodily, affective, cognitive, relational, cultural and historic. Their focus is on the construction of a sense of 'health' also in non-reversible conditions of disease, as they state that chronicity cannot be considered a stable illness condition. They present the Sense of Grip on chronic disease (SoGoD), which refers to the narrative sensemaking processes of the chronic disease by means of semiotic functions. Through the analysis of the narrative construction of the disease in such functions, personalized styles of sensemaking of the disease experience can be uncovered and personalized intervention to foster the process of adjustment to the disease/ patient engagement in the healthcare setting improved. Their aim is to overcome the dichotomy between evidence and ethics-based approaches by integrating normative frames and subjective processes in a semiotic perspective leading to a more effective subjective health trajectories and adjustments to chronic disease.

In the next part of this volume, the focus is widened by looking at ethical challenges on a global basis. Knizek and colleagues take a critical look at the Global Mental Health movement's efforts to improve mental health for people living in under-resourced settings by transferring evidence-based practices from Northern contexts to remarkable different Southern contexts. Critics have pointed out that evidence-based practices developed in a Western setting transferred to different contexts might have unethical consequences by pathologizing individuals rather than their sociopolitical-economic conditions. Human rights and ethics-based practices are the ideals of both Global Mental Health supporters and their critics, but inherent in all approaches one can find unforeseen consequences that go against the initial ideals.

Next up is Ikuenobe discussing an African normative conception of personhood, to illuminate the nature of and need for contextualized ethics-based practices in healthcare and suicide prevention. The basis for his argument is an assumption of suicide involving complex issues deriving from lack of material, physical, and psychological well-being, disharmonious relationships in a community and a diminished sense of selfhood. In his argument, he demonstrates that the African sense of personhood consists of social-moral aspects and bio-physical, psychological and metaphysical aspects and involve the internalization of communal norms and moral principles. To achieve moral and psychological well-being and harmonious relationships implies the performance of obligations. This conception of personhood with the important role that community and relationships play in the attainment of well-being is relevant for understanding the issues of health, well-being and suicide among Africans.

From the overall reflections on African personhood as necessary basis for health interventions, we get an insider perspective on ethical challenges from Kibuka Musoke and Hama-Owamparo from Uganda and their work with disenfranchized gender and sexual minorities. In a hostile psychopolitical and legal system that limits and violates the human rights of gender and sexual minority groups, such persons have a set of challenges. Access to competent healthcare with friendly and knowledgeable professionals seems limited compared to the need expressed by individuals within this community. The authors in this perspective chapter are honing on the experiences of a group of gender and sexual diverse individuals highlighting the role of functional meaning in the determination of better mental health and overall well-being.

From Africa, the focus shifts to Asia and Chaudary's focus on ethics-based practices for family-based interventions in the field of early childhood development and care as practiced by International NGOs. She argues that family interventions in the Global South are aimed towards poverty alleviation through evidence-based research without little or no recognition that the primary source of the evidence-base comes from different parts of the world. This gives rise to serious questions about the validity of the evidence itself on account of ideological foundations, methodological bias and ecological variation. In her chapter, she questions the nature of the evidence itself and whether the evidence can be considered universal. Finally, she discusses how this evidence can translate into local practice. She concludes that ethics-based practices must be included in order to account for global-local dynamics in the transfer of knowledge to local contexts.

This volume of annals is devoted to the investigation of what the content of an ethics-based practice might be, and how it should be entrenched theoretically. It presents new perspectives, both on the fundamental theoretical assumptions and dynamics in the situation of treatment, but also on the role of ethics in all small and huge decisions health workers must make in a situation of treatment in different contexts. The closing chapter of this volume thus is a summary of the contributions towards ethics-based practice.

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Chapter 2
Towards an Ethics-Based Logic of Science in Psychology

Sven Hroar Klempe

For the last decades, focus on ethics has been intensified in all research. This is very true when it comes to health research. The background for this intensification is of course that some researches have violated basic rules in treating animals and humans. Thus, the recent ethical code has been to focus on treating both animals and humans humanly. Another factor has also been the revolution of information exchange through the Internet, in which privacy for all of us is at stake. Consequently, ethical considerations and evaluations have been mandatory for all types of research all over the world.

The APA Ethics Code (*see* https://www.apa.org/ethics/code#) includes the conduct of the researchers and how they relate themselves to their own research. In line with this, the focus is on plagiarism, fabricating data, withholding data and correcting discovered errors. All these latter aspects are about honesty, to what extent a researcher is honest to oneself and to others, and therefore it is also included as a general principle under 'integrity', but not further elaborated on or defined.

The term 'honesty', however, forms a good starting point for this chapter. The main question to be discussed here is to what extent ethical values such as integrity and honesty are decisive factors in scientific methods. Although they can be mentioned in an independent chapter on ethics in a textbook on research methods, they are seldomly, or never, included as premises for the methods presented. The reason is quite simply that the logic that governs scientific methods normally is regarded independent from ethical consideration, as logic and ethics are two different and independent sub-disciplines of philosophy. To examine this understanding, we have to take a closer look on the relationship between logic and science and examine what logic actually is about. By focusing on American pragmatism and phenomenology in this examination, we will then turn the attention to those ethical considerations and

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schools that are in line with these philosophies. One of them is the discourse ethical tradition, which was developed by Jürgen Habermas. On this basis, I will finally sketch some premises for developing an ethics-based logic of science.

Logic and Science

As long as logic has been a subject, it has been related to knowledge. This formed the point of departure for Aristotle when he systematized his logical thinking in the so-called 'Organon', which consists of four parts: how to categorize, how to validate statements, how to infer and how to prove (Aristoteles, 1995). The most controversial parts of the Organon are the two latter parts: the so-called "Analytics". They both underline the validity of deduction, i.e. the inference from general to particular propositions. This simple thinking forms the basis for the Aristotelian system for achieving valid and true knowledge. In his *Metaphysics*, Aristotle (n.d.) points out those general propositions that are not questionable and therefore form the general valid statements, the so-called axioms or first sentences, which may form the premises for scientific valid inferences. During the Medieval time, this way of reasoning also formed the method in all sciences and was named the axiomatic method (Dreyer, 1993). Induction, i.e. to infer from the particular to the general, is also treated in the Analytics, but its validity is constrained to how to deal with sense perception and the particular. Neither provides general valid knowledge, and thusly cannot produce logical valid demonstrations. Induction is related to the example, which is used for persuasion and therefore has an important function in rhetoric, but not in Aristotelian logic.

However, this way of reasoning gradually changed during the renaissance, and Francis Bacon redefined completely the role of induction in science with his New Organon published in 1620 (Bacon, 2000). Axioms require accuracy in terms of well-defined and clear concepts. The humanistic movement in the renaissance focused on poetry in which language is not always used in line with precision and clarity, and the early emergence of psychology in the sixteenth century dealt with the most diffuse terms like *the soul*, *passions*, and *sensation*. On this basis Bacon formulated one of his aphorisms, he called them, which may summarize the background of the turn from deduction to induction as the basis for the logic of science.

> The syllogism consists of propositions, propositions consist of words and words are counters for notions. Hence if the notions themselves (this is the basis of the matter) are confused and abstracted from things without care, there is nothing sound in what is built on them. The only hope is true induction. (Bacon, 2000, p. 35 (Book 1, XIV).)

Among other factors, *The New Organon* of Bacon paved the way for British Empiricism.

During the twentieth century, however, deduction returned gradually as almost the only accepted valid type of inference in scientific logic, yet without the same trust in axioms. Instead, guesses and conjectures in terms of hypotheses formed the premises in a deductive inference from the general to the particular. Karl Popper (1980) became most famous for this, although he was not the only scholar arguing for hypotheses as the basis for scientific knowledge. Yet, he added also the criterion of the crucial test in terms of falsification. As long as the hypothesis is not falsified, 'it may well be true in fact, even though *we do not know, and may perhaps never know, whether it is true or not*' (Popper, 1978, p. 115, italics in the original). What we actually may know something about, however, is the counterexample that eventually falsifies the hypothesis that is at stake.

The latter forms a crucial aspect of the logic of science, and it brings us into a deeper conflict between deduction and induction. *If the counterexample is the only thing we can be sure about, then any verified example should be sufficient to have knowledge about this particular event.* This conclusion is an argument for dealing with case studies in research, and it forms the background for all types of qualitative research, which normally does not pretend to generalize, but just to deal with examples that confirm them. From a logical point of view, the latter is sufficient to say that this example is actually true. But the question is: do case studies and qualitative research just stop there, and in fact do not generalize at all? The answer is No. The reason for this is that scientific discourse is captured in terms, and terms are general. Although I can refer to a certain case, for example a certain child. However, when I use the term 'child', my interlocutor, who does not know this child, will eventually refer to another child, or think about a child in general. This is why we can understand each other through language, namely that the concepts are general and abstracted from the actual events the concepts may refer to. Yet, this makes also that language only provides general knowledge and that there is an insurmountable gap between specific and secure knowledge about the reality on the one side, and the knowledge provided by language and thinking on the other.

On this background, the philosophy of science is highly focusing on *bridge principles*, i.e. 'how the processes envisaged by the theory are related to empirical phenomena with which we are already acquainted' (Hempel, 1966, p. 72). The way Carl G. Hempel uses this term refers primarily to natural science. He relates bridge principles to those cases where there are some unobservable aspects, such as 'moving molecules, their masses, momenta and energies' (p.73). In those cases, the event has to be compared with similar events that have already been explained. This requires also another type of guiding principles, which are the 'internal principles'. These principles say that the explanations of such entities and processes have to be 'invoked by the theory and the laws which they assumed to conform (p. 72). However, other philosophers may have a broader understanding of bridge principles, as they represent those rules that 'connect theoretical terms with observational terms' (Føllesdal & Walløe, 1977, p. 76), i.e. the general with the particular. This implies that the general understanding provided by terms and theories cannot be directly connected with the actual and particular reality unless these connections are specified by means of these bridging rules. Thus, these principles underline the fact that there is a fundamental gap between a general understanding of events and the specific and actual event itself. This is the reason behind developing scientific methods; they aim at compensate for this gap by mitigating the distance between the two aspects.

What is Logic?

On this basis, logic has its limitations in forming the basis for scientific methods. One of the unsolved questions is the status of the hypothesis. Popper tried to make a distinction between a random conjecture and a scientific hypothesis by the criterion of falsification, which is another way of formulating the need for bridge principles. The hypothesis must be formulated in such a way that it provides a crucial test, which implies that the hypothesis has to generate test implications. Popper (1978) talks anyway about 'degrees of testability' (pp. 112–135). Thus, falsification as a criterion for demarcation between science and not science has been criticized from different perspectives. The most challenging question is if we are approaching a truer understanding through eliminating all the falsified theories.

Although he died when Popper was just 12 years old, Charles Sanders Peirce was one of those who criticized the thought that we will approach closer to the truth by excluding all false ideas. Take all observations you may do of, for example temperature, and place them as points in a diagram. We normally think that the curve has to be the shortest way between each point. However, there might be a lot of observations that have *not* been done. They may lie between the actual points and therefore generate points that may change the shape of the curve radically. The curve represents a theory, and since there is a possibility for an endless number of curves that may cover the actual points in a graph, there may potentially exist an infinite number of theories that may explain the observed events too. If even an abundance of theories are falsified, there are potentially still an infinite number of theories left to falsify. The infinite minus a specified number is still infinite. Falsification, therefore, does not bring us closer to the truth (Skagestad, 1980, p. 72).

On this background, Peirce spent more or less his whole life on investigating the relationship between rational thinking and the sensed reality. This is first of all summarized in the term 'abduction', which is hard to define and explain. It is often presented as a third alternative to induction and deduction, yet according to Peirce, it is a term that primarily refers to the role of hypotheses in scientific reasoning (Peirce, 1994). It catches the transitional moment in which a perception of a particular event in a particular moment is put into words, and by the latter includes immediately a general perspective. As a perceived event always can be described from at least two different perspectives and therefore provide at least two different interpretations, each one of them have to be a hypothesis. Abduction, therefore, is first of all about how hypotheses appear, which is the same as when the particular is transformed into the general. Thus, the term 'abduction' can never replace deduction or induction as a logical inference. It rather aims to catch the more or less mysterious gap between the particular and the general, and by this makes us in fact aware of how fateful the transition from the particular to the general actually is. In science, there is a tendency to not admitting the crucial aspects of this transition, which evoke exactly the question about honesty in science.

Yet, there is more to learn from Peirce, and not least from how he understands the status of logic. He was occupied with this question during his whole productive life. The term ‘abduction’ came up on a late stage, just after 1900, whereas in the 1860s and 1870s, he presented a quite radical perspective saying, ‘Logic is rooted in the social principle’ (Peirce, 1878b/1986, p. 284). This means that the laws logic follows are given by conventions and therefore something we have agreed upon. They do not have an independent ontological status but their existence ‘belongs to a community’ (Peirce, 1869/1984, p.271). If not, both logic and our understanding of the real would have been completely private.

> The real, then, is that which sooner or later, information and reasoning would finally result in, and which is therefore independent of the vagaries of me and you. Thus, the very origin of the conception of reality shows that this conception essentially involves the notion of a COMMUNITY [sic], without definite limits, and capable of an indefinite increase of knowledge. (Peirce, 1868/1984, p. 239.)

This implies that logic is not more fundamental than other conventional rules, like norms and morality, just that we have the capacities of following and reflecting upon rules. Conventionality does not make the rules less constraining, but they are either not strongly fixed.

As mentioned in the quote, this is also the case when it comes to Peirce’s understanding of scientific truth. In one of his most famous articles, ‘The Fixation of Belief’ (Peirce, 1878a/1986), he underlines the role of feelings as guiding principles in the process of acquiring scientific knowledge. What drives us to investigate and search for new knowledge is quite simply that the ‘irritation of doubt causes a struggle to attain a state of belief’ (Peirce, 1878a/1986, p. 247). The struggle he refers to is in fact the actual inquiry done. The criterion for having achieved results that can be said to be true is ‘the feeling of believing’ (p. 247). These thoughts may sound as pure psychologistic perspectives on the process of acquiring scientific knowledge and the foundation of logic. Although he tried to free logic from psychology by letting it be entrenched in conventions and agreements formed by a community, he never managed to overcome the fundamental logical gap between inductive and deductive inferences. The introduction of ‘abjection’ was a nice try, but still it is hard to understand how this can work as a valid inference (Douven, 2017).

All these challenges connected to logic have followed the discipline since Aristotle was rediscovered and brought in as a scholarly authority by Thomas Aquinas. Already John Duns Scottus (1256–1308) presented doubts about the general as the only basis for saying what is real. In the renaissance, there was a scholarly movement against Aristotle, with a certain attack on the distinction between deduction and induction. Moreover, this was based on not accepting any clear distinction between rhetoric and logic. Francis Bacon’s *The New Organon* (2000) from 1620 must be regarded as one of the many peak points of this rebellious movement against Aristotle. Bacon’s thesis may count as a landmark for how psychological factors like perception and subjectivity became crucial factors in philosophy. They did not only influence British Empiricism but also German Rationalism, as psychological factors represented Immanuel Kant's main concerns in his critical writings. Husserl's phenomenology must be understood as a direct consequence of the dominance of psychological factors in philosophy. In line with the late Peirce, he also tried to avoid psychologism as the basis for logic (Husserl, 1970). According to Husserl, psychology 'deals with thinking as it is, logic with thinking as it should be' (p. 41). Thus, logic is regarded as a normative discipline, but the rules that govern logic concern only thinking and not its relationship to the reality. By defining logic as a normative science, it is not completely detached from morality. However, as long as logic is defined as a pure science, it is quite independent, also from the reality. Consequently, logic is comparable with chess, as they follow their own game rules, with little or no interchange with the reality. Logic, therefore, has nothing to contribute with in the understanding of a transition from a thought to the actual reality.

The Linguistic Turn and Hermeneutics

The philosophy of the twentieth century is characterized by the so-called linguistic turn. Ludwig Wittgenstein is often regarded as the prominent representative for this turn (Glock & Kalhat, 2018). Yet, Wittgenstein presented two very different philosophies: the positivistic *Tractatus Logico-Philosophicus* from 1921, which focused on an ideal use of language as the decisive factor for achieving scientifically preciseness. The later Wittgenstein, on the other hand, rejected this thesis and replaced it with the thesis *Philosophical Investigations*, which he wrote during World War Two (Wittgenstein, 1945/1958). In this, he presented the term 'language game', which says that the rules that govern language are primarily the context and the way language is used. Language, therefore, is not given a priori, but is rather a result of the actual process in which it is used. Language still follows rules, but the rules are not given a priori, but are results of the linguistic community.

The 'linguistic turn' refers primarily to philosophy in the twentieth century. However, it represents a continuation of a line that can be traced back to the Renaissance and the philosophical turns that appeared in the eighteenth century. Giambatista Vico's (1668–1744) tenet, *verum factum*—the truth is created (Tateo, 2017) is a good representative for the turn at that time. There are many ways to understand this expression, but one of the most radical aspects of it is that humans understand best what they have created. This means that our knowledge is provided by language and the history, which is created by humans. In line with this, he developed a poetic metaphysics, and a poetic logic (Vico, 1744/1999). He applied the term 'logic' in its original meaning, which refers to 'word', 'wisdom' and 'knowledge'. As a professor in rhetoric, he followed up the scholarly movement that did not accept the Aristotelian absolute distinction between deduction and induction. His thesis on what he called the *New Science* (Vico, 1744/1999) had tremendous influence on the development of hermeneutics in the nineteenth and the twentieth centuries.

Hans Georg Gadamer (2013) is one of those scholars, who places Vico in the forefront. He highlights how knowledge in general is entrenched in language and situated in a community in terms of common sense. In the same vein, Gadamer also refers to Baumgarten, who is also of interest when it comes to the variety in the understanding of logic. Baumgarten (1750/2007) introduced the neologism ‘aestheticological’. This term targets directly the mysterious crossing point between the general and the particular. The term is introduced where he apparently presented his aesthetics; yet, the thesis was even as much a contribution to the discussion on crucial aspects of the theory of knowledge at that time. The main concern was about how general thinking can be related to the particular provided by sensation. Although, this term has not survived, the content is still relevant, as Gadamer (2013) highlights Baumgarten’s understanding of judgment in the light of the unity between the two perspectives: ‘[J]udgment does not simply mean applying a pregiven concept of the thing, but that the sensible individual is grasped in itself in so far as *it exhibits the agreement of the many in the one*’ (p. 29 italics added). The exhibition of the agreement of the many in the one is the aestheticological process; it is when subjective truth corresponds with general truth.

Critical Theory

One of those who followed up Gadamer’s hermeneutics, but placed it into a much broader perspective is Jürgen Habermas. For him, the dialogue, the conversation and the discourse are the devices, through which we not only understand each other but the world and not least the society. In the 1950s, he became affiliated with the Institut für Sozialforschung in Frankfurt (Honneth, 2009), which had been the centre for critical theory since 1923. Max Horkheimer was the leader, but Theodor W. Adorno was closely associated. Because of the Nazi-regime in Germany, it closed down in 1933, but reopened again in 1950. Critical theory became a cross-disciplinary neo-marxistic movement, which had tremendous influence on scholarly thinking in the academia almost all over the Western world in the 1960s and 1970s.

When Habermas started as an assistant to Adorno in the mid-1950s, he was not completely in agreement with the main ideological direction of the institute. Habermas was ideologically more entrenched in hermeneutics, American pragmatism, the linguistic turn and partly Kantian rationalism. Critical theory had problems with all these theoretical directions, but Habermas has all the time combined his own thinking with the critical attitude in critical theory. All these aspects are summarized in the main two volumes work of Habermas: *Theorie des komunikativen Handelns*—The Theory of Communicative Action, from the 1980s. The crucial aspect of this theory is that the involved persons in a group or the society try to announce and coordinate their plans and aims for actions and the ground on which they are based

(Lafont, 2009). It is, in other words, about clarifying the intentions one may have and that these are articulated in the public sphere in which they might be relevant.

This is in line with the core of the ideology that guided critical theory. The main message from Horkheimer, Adorno and Marcuse was that all research, and especially in social sciences, should, with a distance, comment on the actual society in which it operates. Being critical is not about being negative, but to aim at uncovering the hidden conditions on which the society is based. Although those three scholars came with harsh attacks on Popper and positivistic main stream research around 1960, this was not an attack on quantitative research as such, but on the fact that this research was not guided by the idea of revealing the hidden conditions on which the society is founded. For example, Adorno worked in a more or less positivistic-oriented research group under Paul Lazarsfeld at Princeton University when they both were exiled in USA during World War II. Adorno also wrote an article in the mid-1950s, in which he argues that empirical research can very well be critical (Adorno, 1957/1998). Thus, according to critical theory, to be critical is not a question about method, but about a certain attitude—to be aware of the different types of interests that are involved in the actual research. This is the main difference between critical theory and Popper's critical rationalism (Popper, 1978). The latter refers to a distance from rationalism that presupposes the Cartesian doctrine saying that the truth is obvious. Thus critical rationalism is about making the research empirically founded, whereas critical theory is about focusing on the attitudes and interests that are embedded in research.

Discourse Ethics

Rationalism, therefore, may refer to different aspects of being reasonable. For Popper, it was important to formulate the demarcation criterion between science and non-science. The so-called 'crucial test' is for him a symbolic formulation for making science empirically grounded. The logical reason of this led to the fundamental criterion of 'falsification'. By means of this criterion, he did not have to include too many ethical considerations in scientific reasoning. When the critical tradition, on the other hand, included interest as a core factor in all human acts, neither philosophy nor science can ignore the ethical implications this may cause. Thus the fundamental question is to what extent it is possible to achieve any type of valid knowledge if all scientific results are embedded with hidden interests. The answer Habermas gave was based on two factors that have to be taken into account. One is the dialogue, and the other is a broad understanding of rationality. The latter is about our longing; not only for truth but also that the truth is universally valid. On the one hand, we are searching for this, yet, on the other hand, each one of us has an own opinion about something, which is regarded to be the true one. Additionally, when we can agree upon something, there will be no doubt about the truth. Accordingly, when all thought the earth was flat there were no doubts about what was true. However, in retrospect, after we discovered that the earth was in fact round, we also have the opinion that the earth has never been flat. Thus, what we may agree upon will be considered as a universal truth. Rationality, therefore, is a longing for universal truth, which also includes the chances for not having accomplished the truth. In principle, there will always be a chance for having a false opinion, but what we can agree upon will anyway be the closest we can come the truth, and therefore also the most true we can achieve. This is also an aspect of rationality, namely that we can agree upon what the majority considers as representing the truth. Yet, to come there, there is still one criterion that has to be followed, and this is the ethical aspect of the research process, as many aspects, factors and interests as possible have to be uncovered, presented and discussed in public. This process of agreement is the discourse, which Habermas means generates a complete ethical system, but is also decisively involved in all actual research.

The ethical implications of research is thus not only a question of how we act but even more a consequence of how we use and deal with language. Habermas was quite influenced by the Oxford philosopher John L. Austin's speech act-theory (Niesen, 2009). By making a distinction between the statement (locutionary act), the simultaneously performed act (illocutionary act) and the obtained consequence (perlocutionary act), truth is not just a result of a statement's ability to accomplish a proper description of the fact. William Blake is probably the one that has grasped these discrepancies in the use of language best with the formulation: 'The truth that is told with bad intent, beats all the lies you can invent' (www.goodreads.com). The perceived consequences of these discrepancies are though the most crucial part. This is why American pragmatism also plays an important role in Habermas' philosophy (Rizvi, 2009). Although, Habermas primarily refers to John Dewey, William James is the most important reference also for Dewey when he tries to explain what pragmatism is about (Dewey, 1907/1998). According to James, the fundamental thesis behind pragmatism goes like this: 'Our conception of [the] effects, whether immediate or remote, is then for us the whole of our conception of the object, so far as that conception has positive significance at all' (James, 1902/1977, p. 378). This tenet says that the world, but first of all *our conception* of the world, is always in transition, which means that the truth will always change as well. This dynamic factor is crucial for leaving the conception of the truth as something stable and given once and for all. Thus, these perspectives have tremendous consequences for how to deal with the research and for the role of logic as the basis for scientific reasoning. The gap is not only between the logical distinction between deduction and induction but also between the perceived world and our actual use of language.

In this perspective, the experiment in terms of a scientific attitude is the solution that permeates Dewey's thinking. His slogan 'learning by doing', for example, requires the premise that the children shall be given the opportunity in school to pursue their own curiosity by formulating what occupies them as a research question and perform the required investigation (Dewey, 1938). Thus, the pupils are not only active in performing experiments, but the learning situation is also a free democratic process. Consequently, there is no difference between the principles that guide a learning process in school and the principles behind an ideal democracy.

> An American democracy can serve the world only as it demonstrates in the conduct of its own life the efficacy of *plural, partial and experimental methods* in securing and maintaining an ever-increasing *release of the powers of the human nature*, in service of a freedom which is *cooperative* and a *cooperation*, which is *voluntary* (Dewey, 1939/1998, p. 365, italics added).

This emphasis on a cooperative cooperation may also summarize the core idea behind what Habermas calls ‘discourse ethics’ when Habermas defines the principle for it by saying ‘. . .norms can only be declared as valid when they are provided by an actual discourse among participants and achieved a consent for all concerned (or might be able to find)’ [‘. . .auf dieser Basis schlägt Habermas den diskursethischen Grundsatz “D” vor, dem zufolge “nur die Normen Geltung beanspruchen dürfen, die die Zustimmung aller Betroffenen als Teilnehmer eines praktischen Diskurses finden (oder finden könnten)’](Forst, 2009, pp. 236–237).

An Ethics-Based Logic of Science (Conclusion)

After this examination of the logical foundation of science, there are reasons to sum up and formulate more clearly each step of the different stages of reasoning that point towards an ethics-based logic of science. First of all, there are reasons to highlight the fact that logic is a normative science (Husserl, 1970) and consequently restricted to a certain part of human’s thought processes:

- *Logic is primarily a rule system about the way we should think.*

The rule system that governs logic is not given as an inborn capacity, but a result of interpersonal negotiations about the norms that guide a certain culture’s way of making inferences (Peirce, 1878b/1986):

- *The rule system in logic is entrenched in ‘the social principle’, and therefore a conventionally given rule system.*

In Western culture, Aristotle’s principles for logic dominate so tremendously that deduction forms the overarching basic principle, or a kind of a ground zero for logical inferences:

- *The fundamental valid inference in logic is deduction (Aristotle), i.e. to infer from the general to the particular.*

Even Aristotle discussed induction, but primarily in connection with rhetorical persuasion. A distinction between logic and rhetoric was questioned during the Renaissance in Western history. This paved the way for Francis Bacon (2000) and the British empiricists to build scientific inferences on induction:

- *Induction may open up for inferring from the particular to the general.*

Even today, no one will accept induction as a valid logical inference, and therefore Popper (1980) already in 1939 reintroduced deduction as the only valid logical inference:

- *Aristotle's main conclusion that induction in this sense is not a valid inference, is still accepted.*

Popper's hypothetic-deductive method is comparable with Aristotle's axiomatic method. The difference is that Popper replaced axioms with hypotheses. However, hypotheses or conjectures are not more in line with the actual reality than metaphysically founded axioms:

- *Thus, there is a huge and in principle insurmountable gap between knowledge achieved by logical inferences, which have to follow the principle of deduction, and knowledge acquired through sensation (observation) based on induction.*

Charles Sanders Peirce tried to bridge the gap:

- *Other types of inferences (like abduction and the likes) do not mitigate the gap.*

Hempel (1966) also tried to bridge the gap:

- *Neither do bridge principles mitigate the gap, as they rather emphasize the gap.*

Sensations are directed towards particularities, and all empirical-based inputs stand in opposition to the nature of language:

- *The nature of language is that it transforms particular observations into concepts, which are general.*

Generalizations are not the problem, as we always generalize as long as we use language:

- *This transformation process makes that all observations of particularities are immediately transformed into general knowledge.*

Even the early and positivistic Ludwig Wittgenstein realized that language was crucial in the process of acquiring scientific knowledge, and therefore he highlighted the importance of logic:

- *Knowledge, therefore, is embedded in language, and this is the linguistic turn in theory of science.*

But the second version of Wittgenstein's philosophy realized that logic, as Peirce also had pointed at, is a language game. But it was John Dewey (1932/1998), who followed up Peirce on this point:

- *Knowledge can never be detached from morality and moral judgments.*

Jürgen Habermas was influenced by American pragmatism, and especially John Dewey:

- *Knowledge, therefore, is a consequence of how we deal with language in the scientific community.*

Thus the ethical implications of our use of language will by necessity have consequences on the way we deal with knowledge:

- *The bridge principles that connect thinking with reality have to be redefined by not only focusing on technical conditions, but also on ethical aspects.*

Then we are back to the starting point, in which we can specify what honesty, integrity and dignity should be about:

- *The bridge principles have to be about the degrees of honesty, integrity and dignity, or in short, about the individual researcher's interests.*

The main conclusion of this examination should therefore be:

- *As the term 'logic' originally is a broad term that also includes rationality, an ethics-based logic of science has to be about taking the gap between deduction and induction seriously into account and consequently define the bridge principles ethically in terms of levels of honesty, integrity and dignity.*

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Chapter 3
Clinical Practice: Ethics Before Evidence!

Tor-Johan Ekeland

Clinical Practice: Ethics Before Evidence!

Since the 1980s, most Western countries have been motivated by the ambition to modernise welfare states by making services more effective, transparent and accountable (Ekeland, 2021; Hood & Dixon, 2015). In this context, evidence-based practice (EBP) has become an attractive concept, the new game in town, recommended by stakeholders in the WHO to national and local authorities as the best way to ensure effective, efficient, ethical and accountable practice in treatment. The label has also been used as a trademark by almost every profession to legitimise itself and its methods. From an ethical perspective, the strongest arguments in support of EBP are that it allows professionals to make better-informed decisions, identify and avoid useless or harmful methods and thus maintain high-quality professional practice based on science.

In this chapter, I will oppose this promising view on EBP as a new outlook and the best way towards ethical practice. On the contrary, when it comes to the mental health field, the epistemological ambition implicated in EBP is old. Furthermore, there is no empirical evidence showing that an applied psychological practice such as psychotherapy is evidence-based. Finally, the history of therapy and treatment shows that clinical practice based on such an epistemology is no guarantee for an ethical practice—in some cases, it could even increase the inhumanity rather than protect us against it, as ethical problems cannot be solved by science.

Since EBP has been branded as a panacea to ensure high scientific and ethical quality in practice, it is worth remembering Garret Hardin's (1985) remark about dearly bought experience from history that impressive ideas can have impressive, perverted consequences. One reason for this, according to Hardin, is that our

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understanding of the world is too simple compared with reality's complexity and relatedness. Hardin, leaning on system theory, is in accordance with what Gregory Bateson, another system theorist, called epistemological errors—a kind of mismatch between map (epistemology) and territory (ontology), using a metaphor (Bateson, 1979). The problem with epistemological errors, says Bateson, is that in the long run, they will reveal themselves in practice through their problematic consequences. The history of treatment in psychiatry and the mental health field is also a history of wrongdoings and inhumanity. I will argue that these wrongdoings in clinical practice cannot be explained either as moral or intellectual incapacities; they are deeply anchored in an objectifying epistemology which puts the other in the perspective of a general scheme within a scientific horizon to reduce the subject (the person) into something objective (the other). An uncritical adherence to EBP in clinical practices could foster such a risk.

What Is Meant by Evidence-Based Practice?

As a concept, EBP was originally born as evidence-based medicine (EBM), inspired by two sources: The work of Archibald Cochrane and colleagues at Oxford, UK, which culminated in the establishment of the Cochrane Collaboration in 1993, and the development of clinical epidemiology at McMaster University in Hamilton, Ontario, Canada (Morago, 2006). From the Canadian milieu, the 'Evidence-Based Medicine Working Group' emerged. In 1992, this group published a programme for what they characterised as a new paradigm in medicine. However, the *new* aspect of this paradigm was foremost a systematic method to strengthen medical decision-making by including research evidence from clinical epidemiology, based on randomised controlled trial (RCT) design and meta-analysis (Guyatt et al., 1992). Later, scholars from this group formulated the most cited definition of the concept to date, describing EBM as '. . .the integration of the best research evidence with clinical experience and the user's preferences' (Sackett et al., 1996, p. 71). In 2001, The New York Times chose EBM not only as the idea of the year but also as one of the most important medical milestones of the last 160 years (Hitt, 2001). The concept has since spread from medicine to nearly every kind of practice in welfare states. Moreover, the classic definition with its three elements (research evidence, clinical experience, and user's preference) has been adapted for different kinds of professional practice, and in the definition of psychology by the American Psychological Association (2006) and the Norwegian Psychological Association (Norsk psykologforening, 2007).

As within most professions, EBP has been received with both enthusiasm and criticism in psychology. However, the push to promote EBP has been the overriding force, driven by both the professions themselves and pressure from authorities. Its branding as 'scientific' has given its proponents a moral upper hand to claim that it is their moral duty and ethical responsibility to offer treatment that is scientific and known to work (McNeece & Thyer, 2004). This focus on professional accountability and ethical responsibility towards clients and the community has become an argument for intensifying the implementation of EBP in ordinary service. Hence, EBP is no longer considered only an option for the professional, but also a way of organizing normal practice. In many countries, diverse top-down government projects have been developed to strengthen adherence to EBP; in fact, enforcing EBP has become a political demand (Høgsbro, 2015).

Critics have characterised EBP as an ideological movement with a seductive rhetoric, accusing it of disregarding reason on behalf of rules and algorithms produced by the guidelines industry, promoting cookbook practices and ignoring the complexity of clinical practice. It has also been labelled a governmental managerial tool that ignores power and politics and gives inadequate consideration to individual and cultural differences (Barratt, 2003; Crisp, 2011; Ekeland, 2009; Evans & Hardy, 2010).

What Is the Evidence that Validates EBP?

The cited definition of EBP by Sackett et al. (1996) is idealistic and hardly controversial at face value. Nevertheless, the debate has been heated, and on the operational level, it seems that EBP eludes a precise definition, with confusion surrounding the meanings of both 'evidence' and 'practice'. In our context, we should distinguish between evidence-based *knowledge*, which concerns what counts as evidence, and evidence-based *practice*, which concerns the measures and procedures that implement this knowledge into practice. Regarding the former, EBP makes epistemological claims about the relation between theory and practice by defining the criteria for what should count as knowledge and predicting that this knowledge will give the 'best practice'. Best knowledge (or evidence) should follow a methodological gold standard, where RCTs and meta-analysis of studies with such designs are at the top of the hierarchy. Other sources of knowledge (e.g., sources based on qualitative studies) rank at the bottom of the hierarchy and are only admitted in review, e. g. from Cochrane and Campbell, if the RCT is at the top. Implicit in this approach is the principle from chemotherapy's double-blind design: One is to prove that a method affects a specific condition independent of who performs it, the situation in which it is practised and other characteristics of the patient that are irrelevant to the condition. Simplified, this kind of study reveals that a treatment or measure works well for an average patient/client within a diagnostic group compared with an average patient/client in a control group. There is, however, a difference between statistical and scientific inference and between what is significant in research and in practice (clinical validity). An average patient is furthermore a construct never encountered in real life. The clinicians always meet a *person*. Whilst the knowledge from RCT and meta-analysis is relevant regarding the population level, which is the main interest for the authorities, its relevance is more limited at the personal level. In addition, it is hazardous to draw inferences from what counts on the level of aggregate to the single case since treating a patient just as a specimen in a category (diagnosis) could result in evidence-*biased* practice.

What Is the Scientific Aspect in EBP?

What about the claim that makes EBP scientific? Addressing ‘what works’ more so than ‘why it works’ makes EBP an example of empirical pragmatism rather than of scientific enquiry. To elevate a particular design (RCT) as generally better than others is contrary to the recommendations in most textbooks on scientific methods; these methods should be adapted to the research problem. Furthermore, the epistemological claim behind EBP is very old: To develop knowledge that is objective and independent of context, which, as such, could be transformed into some kind of treatment with the character of a ‘technology’. A ‘technology’, metaphorical speaking, is a kind of knowledge that comes in a package so that when a specific problem is defined (or diagnosed), a specific known technique (therapeutical method) that is known to be appropriate could be applied to solve the problem.

What is new in EBP is not this epistemological claim but rather its *practice*. Whereas the original definition presupposes professional discretion in determining the influence from the aforementioned three elements (research evidence, experience and user’s preference), it seems that EBP now has merged with neoliberal governance and performance technologies, advocating certain methods or manuals for specific problems, thus leaving less room for professional discretion (Ekeland et al., 2018). If professionals choose otherwise than the guidelines recommend, they are at risk of being held personally accountable if something goes wrong. Neoliberal governance has therefore resulted in increased standardisation, application of protocols and heavy-handedness of bureaucracy regarding data collection and documentation for production and benchmarking, audits and accountability, transparency and economic efficiency. In this context, EBP has been transformed from an ideal into a reality. When the element ‘best research evidence’ in EBP is decided by managerial instructions outside the clinical context and the clinician’s discretion, the original definition of EBP is violated. The standardisation and ‘technologification’ of practice based on EBP could be unproblematic when the relationship between measures (input) and effects (output) is stable and the predictive validity is high. As will be shown, this is because of epistemological reasons, seldom the case in practices based on communicative interaction between helpers and service users, for instance, psychotherapy.

Psychotherapy and Its Ambition to Be Scientific

Until the Second World War, psychotherapy was synonymous with a rather esoteric practice rooted in a psychoanalytic or psychodynamic tradition. When psychotherapy expanded and moved into public healthcare systems after the war, it became compellingly necessary to legitimise it in the academic society and in relation to governments and stakeholders, as well as in society. Psychology, with its post-war expansion as an academic discipline in Western universities, gradually adopted a central mission on behalf of the profession of psychotherapy: To accumulate scientific knowledge to guide practice and strengthen clinical service. This scientific ambition found its explicit imperative at the 1949 Boulder Conference, where the profession of psychotherapy declared its allegiance to the goal of integrating science and practice, casting the field in the *scientist–practitioner model*, which has since been adopted by most professions in psychology in the Western world (Boisvert & Faust, 2003; Frank, 1984).

The questions before psychotherapy could be put on a scientific footing were these: Does psychotherapy work? And if it does, how and why? The interest in answering the first question intensified after Hans Eysenck, a dedicated behaviourist, caused a stir in the 1960s by making the following claim: psychotherapy has no proven scientific effect, and psychoanalysis could even have negative effects. This claim, derived from his evaluation of 24 effect studies (Eysenck, 1952, 1969), generated much debate and research to counter it, e.g. see Luborsky et al. (1975) and an overview in Bergin and Garfield (1994). A turning point occurred later with the publication of Mary Smith and Gene V. Glass's (1977) study titled 'Meta-Analysis of Psychotherapy Outcome Studies' in the *American Psychologist*. The sensation created by this study stemmed not only from the documentation that Eysenck was wrong (there are many reviews and studies supporting that psychotherapy does indeed work) but also from the fact that the conclusion was based on the first meta-analysis—a statistical analysis seen as a breakthrough in scientific studies of treatments. This is peculiar since meta-analysis estimates effects based on the lumping together of many RCT studies. If you have to go to such a level of aggregation to document therapeutic effects, it no longer seems an impressive scientific reason for applying the therapy at the individual level.

The Dodo Bird

This breakthrough, however, only answered the first question; psychotherapy does work. With relevance to the questions on *how* and *why*, Smith and Glass (1977) concluded that 'despite volumes devoted to the theoretical differences amongst different schools of psychotherapy, the results of research demonstrate negligible differences in the effects produced by different therapy types' (p. 760). The possibility that psychotherapy could not have specific effects was not a new allegation; Jerome D. Frank (1961) argued this in his book *Persuasion and Healing: A Comparative Study of Psychotherapy*, and as early as 1936, Saul Rosenzweig made the same claim in an article when he alluded to the verdict of the Dodo bird in *Alice's Adventures in Wonderland*, whereby the Dodo bird declared, 'Everybody has won, and all must have prizes' (Rosenzweig, 1936). In a review of empirical studies, Luborsky et al. (1975) drew a similar conclusion to that previously made by Rosenzweig, canonising the term 'the Dodo bird verdict' in psychotherapy. The Dodo bird verdict is a fundamental threat to the ambition of psychotherapy to be an applied science. Extensive evidence in the history of empirical research on psychotherapy has tried to falsify it without success. Furthermore, evidence shows that specific theories and techniques have relatively little to do with effectiveness in psychotherapy; rather, common factors, particularly interpersonal factors, are the primary agents of change. Moreover, the therapists and clients' belief in the methods are more important than the methods per se (see, e.g. Baldwin & Imel, 2013; Duncan et al., 2010; Elkins, 2007, 2012; Lambert & Barley, 2002; Norcross, 2011; Wampold & Imel, 2015, Boisvert & Faust, 2003). The editors of *Handbook of Psychotherapy and Behavior Change* had already concluded 27 years ago that 'there is massive evidence that psychotherapeutic techniques do not have specific effects, yet there is tremendous resistance to accepting this finding as a legitimate one' (Bergin & Garfield, 1994, p. 822). This situation has not yet changed.

From a historical perspective, this resistance is understandable. Knowledge, which can be transformed into technology, gains its societal status because it gives hope, not only to make products and solve problems but also to do it in a standardised way. They who master knowledge and its technology are given privileges and gain status as professionals. The name for this kind of practice today is EBP. And to deny, as a profession, the imperative to be evidence-based has become synonymous with denying science. Whilst it is legitimate for a profession to pursue its own interests, a science (like psychology) is obligated to pursue the truth, not interests.

Wampold (2001) has denoted the Boulder Conference ambition to make psychotherapy scientific based on a 'medical model' because the aim, as it is in biomedical medicine, has been to develop a context-free treatment with an acceptable, stable and repetitive causal link between the medicine (input) and its effect (output). If we consider the medical model a hypothesis about psychotherapy, which was put forward at the 1949 Boulder Conference, it is now falsified after nearly 70 years of research and overwhelming empirical evidence—speaking in terms of Karl Popper. However, Karl Popper does not seem to have achieved hero status in mainstream psychotherapy. Even if the specific method explains only a modest range of outcome variance (5–10%), researchers are jumping aboard the EBP bandwagon, hunting down this least important 'ingrediency' in the outcome of psychotherapy (Ekeland, 2009). The hypothesis seems to be adored more than the empirical facts. The reason for this is probably its correspondence with the epistemological architecture in mainstream psychology.

Psychology as Epistemology

We are living in two different worlds: the world given to us by nature and the one made of our own perception and interpretation of it—collectively and individually—accumulated in cultural artefacts such as language. Since we have no direct access to the world, we must be content with our knowledge of it. Epistemology, or the theory of knowledge, is concerned with our way of creating knowledge: how we know what we believe we know, what justifies us in believing what we do and what standards of evidence we should use in seeking truths about the world and human experience (Audi, 1998; Steup, 2016). Since it is impossible to acquire knowledge of the world without forming assumptions (epistemologies) of how it is (ontology), sciences, such as psychology, could never be solely objective as one is always perceiving from an angle.

The empirical state of the art in psychotherapy has become a profound epistemological challenge to psychotherapy's ambition to be scientific in order to legitimise its position as a profession. Even though it is well-documented by empirical research that psychotherapy as a psychological treatment is beneficial, in general, the questions on *how* and *why*, mandatory in science, are still unanswered. How can therapies designed from very different theoretical models apparently have similar effects? How can therapies based on obviously unscientific premises about the world still be useful? The paradoxical findings of outcome equivalence and content equivalence present a serious dilemma because they seem to imply that no matter what a therapist does, the results will be the same.

This mismatch between what psychotherapy is expected to be and what it seems to be according to empirical facts, challenges the identity of psychology and the ambition to become a positive science. This is an old story. In an evaluation of psychology as a science, conducted on behalf of the American Association for the Advancement of Science and the American Psychological Association (APA) in the 1950s, Sigmund Koch characterised the modern history of academic psychology as 'a ritualistic endeavour to emulate the forms of science in order to sustain the delusion that it already is a science' (Koch, 1959–1963). This characterisation continues to have relevance as mainstream psychology can still be accused of having offered the phenomenon and forcing reality to surrender to theory to save its own methods and epistemological positions (Ekeland, 2012).

This insistence on the map as more correct than the terrain is probably a question of identity. Whilst psychology as an epistemic practice is very old, according to most general textbooks, psychology as a science was born in a laboratory in Leipzig in 1879. Wilhelm Wundt (1832–1920) is usually portrayed as the father of psychology, the one who turned it into a science by subjecting psychological problems to the methodological requirements of experimental science. The soul became a natural object to be studied by the detached and objectifying scientific gaze. Scholars from all over the world made a pilgrimage to this laboratory of the 'new psychology'; engineers, physicians, physiologists, philosophers and theologians copied the setups in their own academic institutions. Later, psychology become established as a scientific discipline with its own academic departments. It is a historical irony in this narrative that Wundt himself never saw his experimental psychology as anything other than an attempt to create a more overarching and holistic psychology, which was a psychology based on ethnographic studies of human culture, about which he himself wrote eight volumes (Danziger, 1990).

Epistemological Errors

The ambition to make psychotherapy scientific seems to be based on the epistemology in mainstream psychology. This epistemology presupposes that the domain of psychology exists in an independently pre-given reality (ontology) and that truths about such a reality are attainable through scientific investigation. As a consequence of this scientific discourse, there has been a great deal of research about behaviour, mental states, cognition and responses, but little about action, mentality, meaning-making and agency. Psychology has pictured individuals as more or less passive, mechanistic stimulus–response devices, driven by unconscious or biological forces, or information-processing devices that can split behaviour into variables. The person with agency, acting within a world, a moral ecology and a cultural web of meaning that he strives to master is just the surface matter. In fact, what matters is the machinery and mechanism below, in the realm of causality that makes him tick and go. This has become a position more or less taken for granted in mainstream psychology and psychotherapy research. The aim of the science of psychology then becomes the uncovering of this reality and its machinery—namely, how it works and under what laws it operates (Ekeland, 2012). In practical research, this means to relate behaviour (dependent variable) to possible causes (independent variables), whether they are environmental, biological or cognitive.

This regulative theory of causality has been (and still is) an obsession in psychology—the implication being that without causality there is no science. The obsession with causes and laws can be understood from the perspective of psychology's technological imperative to predict and control. When thinking in causal terms, one also thinks in schemes of reversibility—that is, beyond time and place. In this epistemology, the decision about therapy and treatment is based on prediction. Here is the simple logic: the task for science is to demonstrate that if A happens, then B happens (possibly with a probability). The technological imperative then is: if you want B, do A. This implies the following premises*:* there is a stable relation between A and B that can be replicated and that A is independent of the acting person and the response B is independent of the person who is the target of the action. When are these premises valid? When we, like engineers, intervene within the physical domain, we know that responses are stable, universal, causal and unhistorical. Therefore, the prediction is precise; the A-gives-B relation happens every time—for example we do not need any RCT saying that an airplane works well for an average passenger. Moreover, when we intervene within the biological domain, e.g. with medication, we know that the responses are distributed, depending on the state of other bodily systems and the bodily experience, such as the immune systems and its adaptability. Therefore, there are variances in the responses (effects), so the prediction should be statistical. However, through research, we can accumulate knowledge about the variance and biological factors that create it. In principle, the variance can be known. However, intervention within the human domain is intervention with words where meaning counts. When we use psychotherapy and social methods, we use the language to influence people's thinking, emotion, behaviour and actions. This is meaning-making, and the responses do not follow the laws of physics, or reactions of biological systems, but the rules of semantics and the meaning of meaning systems. Of course, language works—it creates effects, but the prediction of the effect is connected to the relation between the person; it is based on reason, intentions (not casual) and interpretations. As most experienced therapists know, it is difficult to repeat successes; the intervention that was impressive effective with one client at a certain point in time could fall flat another time. Our prediction should be statistical, but the variance is unknown and changeable. The premises that the action A is independent of the acting person and that the response B is independent of the person who is the target of the action is not only untrue in this domain but also meaningless. In this epistemic perspective, the empirical results from psychotherapy research are both understandable and predictable.

To confuse the human domain with what counts in the physical and biological domain may qualify as an epistemological error. Mainstream psychology, according to Leipzig's legacy, is resting on an epistemology, presupposing a universal mind, given as if it is like an object to be studied from the outside by scientific methods. Paradoxically, this is a psychology without a subject. As mentioned, Bateson (1979) characterises such a mismatch between map and territory as an epistemological error. He had this idea from studying both small and big systems and concluded that epistemologies have an ecological character and are part of the flow of information and practice in systems. Accordingly, epistemological errors can result in ecological crisis and breakdowns. The problem with such errors is that it is difficult to tackle them by experience because they also govern experience. Further, they cannot be easily submitted to an empirical test because they generate how we test. That being said, the problems will reveal themselves in practice by their systemic and ecological consequences. As an example, Bateson held a distinction between nature and us, seeing humans in a position to control nature from an outside position, as such an error-generating ecological crisis in our time. The ambition to try to control a system, which you are a part of, takes the risk to destroy itself, unless a crisis within the system restores the systemic balance. The foundation of mainstream psychology in object ontology could be characterised as an epistemological error. To objectify what is subjective, is like trying to control something you are embedded in—a relation having systemic and ecological implications at the cultural as well as at the personal level.

Psychotherapy as 'Human Kinds'

How should we understand a practice like psychotherapy? First, I think it is necessary to remind ourselves of the fact that psychotherapy, defined as treatment by the way of a human relation, is not a scientific creation. Quite the contrary, it belongs to our oldest wisdom that human suffering could be alleviated and healed by the way of words, symbols and meaning, staged by a co-suffering and trustworthy helper in an atmosphere of trust and warmth. The well-known and evidence-based phenomenon of the placebo is witnessing this (Ekeland, 1999). Whilst it has had its status as a source of error in scientific medicine, to be controlled for in RCT, it could, in clinical practice, be released as 'psychotherapy natural'—a human potential for healing by the way of mental processes. Our assumed scientific psychotherapy is capitalising on this resource.

Psychotherapy is a kind of interpersonal healing, which can happen in different interpersonal encounters. However, the therapeutic effects do not follow from an intervention's instrumental and causal capacity but from the person's capacity to use what the therapy, as a context, offers to the healing process. That is why Bergin and Garfield (1994) could conclude the following from their review of research, '...it is the client more than the therapist who implements the change process' (p. 824).

What we formally mean by psychotherapy refers foremost to a kind of discourse and the institutionalised roles and contexts where this discourse works, exploring how life can be lived and the variations and dilemmas in human life, our society and our culture. Such a discourse can only be accounted for in a language and systems of meaning wherein both the therapist and client are embedded. What is going on is not an interaction amongst variables but a dialogue between meaning-making subjects. It takes a common meaning system (epistemic trust) to create this. This is how 'human kinds' behave (Hacking, 1999). Psychotherapeutic methods therefore cannot be universal; they must be legitimised in culture.

The context of healing, as framed by the psychotherapeutic culture, must obviously have some specific qualities. For instance, there should be a method, but as the Dodo bird verdict and non-specificity from psychotherapy research imply, the validity of the theory or method that guides the therapy is irrelevant from a scientific perspective. In that sense, ostensible scientific false theories could create therapeutic effects. This troublesome finding is, however, meaningful if we see such theories as languages. The task of language is to make and communicate meaning. In this regard, one language is not inherently truer than another so they cannot be compared on such a basis. The different therapeutic methods could be considered different languages or meaning-making systems that coordinate communication and actions. As such, we could say that the method or model foremost works therapeutically for the therapist. Without the model, the therapist would not be able to sustain an inner dialogue and create meaning out of the patient's chaotic world, without which no outer dialogue between the therapist and the client could be sustained. What is therapeutic about psychotherapy is its capacity to mend meaning. This implies that 'good practice' presupposes room for discretion and individualisation, not specified in manuals. Uncritical adherence to EBP in psychotherapy could thus undermine the client's position as an autonomous subject.

Epistemology and Ethics

Studying epistemology is important because knowledge defines and creates realities, forms discourses (how we think and speak), exerts power, defines who has the right to speak and which discourses are legitimate, followed by our actions and how we organise our way of handling madness and psychic distress in society. Here, discourse is understood as language and action, a system of meaning that interprets and shapes objects, defines positions and relations between actors and points to certain actions and practices as legitimate or illegitimate (Fairclough, 1995). As such, hegemonic discourses will be embedded in politics, economics and technological and instrumental production. They exercise power and enrol in institutions and appear constitutive of the 'order of things' (Neumann, 2010). Discourses will also define fields of research and fields of practice.

The relation between epistemology and practice can easily be seen in examples from history, both from psychiatry and pre-psychiatric and indigenous forms of treatments. What seems irrational from our perspective could be logically seen from the inside, a hegemonic cultural epistemology. For example if possession by demons is a culturally accepted understanding, exorcism seems an appropriate form of therapy. Reichborn-Kjennerud (1947) describe a cure from Valdres in Norway in the seventeenth century where one, preferably as inadvertently as possible, should slam a rifle shot over the head of the madman—the closer the better effect, was the assumption. Unfortunately, on some occasions, the shot was too close and the 'patient' died. The underlying idea sprang from the epistemology of the 'free soul', which could wander in time and space (as in dreams). In this way, one could lose one's own soul (called 'hug') or it could be stolen or occupied by other beings, including animals (cf. werewolves). With such a diagnosis, scaring the occupant in different ways could be assumed to work therapeutically.

Today the hegemonic epistemology and discourse about madness comes from medicine. It creates subject positions such as patients and therapists and objects such as illness and treatment; it then defines its own language with diagnosis as the current way to speak, being a natural language. However, in a historical perspective, this could be considered medicalisation of madness, starting as a medical gaze on those kinds of human phenomena at the dawn of the eighteenth century, cementing its position as a hegemonic discourse 100 years later. Even if the history of psychiatry has been a struggle between different epistemologies, mainstream psychiatry has been based on the biomedical paradigm; mental illness and symptoms must be primarily seen as consequences of biological defaults (as other diseases), and they can be described and classified (diagnosis) as if they were objects in the world. Consequently, cures and corrections, by implications, must deliver on that level and be able to affect the kind of causality that shapes the disease. The target for the intervention or treatment is consequently the illness, not the person. This is an objectivistic epistemology, implying that mental illness is what Ian Hacking

(1999) denoted as ‘natural kinds’. Natural kinds behave according to known (or unknown) causal laws; the scientific gaze should be the outsiders trying to explain the phenomenon and its behaviour.

Lobotomy as Evidence-Based?

The history of psychiatry is also a history of mistakes and abuses, of professionally legitimised inhumanity (e.g. lobotomy) that we today distance ourselves from. And the list is long, from the mechanical shock measures (fall-limb, tricycle, flywheel) via bath therapies in many variants and defocalisation (surgical removal of teeth, tonsils, cervix, ovary, testicles, gallbladder, colon) to shock therapies using emetics, insulin, cardiazole and anaphylactic shock. Most promising in its time was lobotomy (which led to Egas Moniz receiving the Nobel Prize in Medicine in 1949). ECT (electroshock) also had its period, and currently has, in a renewed version, a recovery (Fosse et al., 2011). From clinical environments, it was most often reported of striking effects, in all cases in the short term. According to the rules in EBP, if we today set up a RCT design, testing the effect of, say lobotomy, it would probably come out as evidence-based. Measured on variables for symptoms and problematic behaviour, the treatment did work. That these effects also turned out to be harmful was a recognition in retrospect.

Epistemic Injustice

Assessing the ethical implications of different epistemologies is of course difficult without gross simplifications. However, regarding mental health patients, the concept of ‘epistemic injustice’, first put forward by Miranda Fricker, seems relevant (Fricker, 2007). It concerns how knowledge (or lack of knowledge) generates oppression and discrimination. Kurs and Grinshpoon (2018) used this concept in analysing why many individuals who have mental disorders often report negative experiences of a distinctively epistemic sort, such as not being listened to, not being taken seriously or not being considered credible because of their psychiatric conditions. They argue that epistemic injustices also affect individuals with mental disorders not only whilst communicating with their caregivers but also in the social context as they attempt to reintegrate into the society and resume responsibilities as productive citizens. A popular view amongst psychiatrists has been that biological explanations for mental disorders, by making patients appear less accountable for their disorders, could increase empathy and reduce stigma. The campaign and rhetoric in the 1990s to speak of mental illness as ‘diseases just like other diseases’, played on this assumption (Whitaker & Cosgrove, 2015). However, most evidence points to the contrary; biological explanations evoke less empathy and can exacerbate perceptions of patients as abnormal, distinct from the rest of the population, meriting social exclusion (Lebowitz & Ahn, 2014).

The historical wrongdoings in psychiatry cannot be explained away either as moral or intellectual incapacities as they are deeply anchored in epistemology, or how the disease was conceptualised. Ethics is not only about virtue and conduct but is also a matter of epistemology. Even if no epistemological tradition can free itself from historical wrongdoings, the risk for inhumanity is, in my opinion, greatest when our way of thinking is based on an objectivist epistemology, seeing mental distress as natural kinds.

Professional Practice: The *Person* as the First Perspective

Therapeutic thinking in Western society during our time has created a problematic mismatch between what psychotherapy pretends to be and what it does and can be. It pretends to be scientific and objective; however, as a practice, it is normative. Its language explains and attributes causality (*erklären*), but what is going on in practice is an interpretative and hermeneutic discourse (*verstehen*). Although scientific knowledge about individuals comes from contextual statistical aggregates of individuals, a therapist meets unique subjects and persons, who are impossible to know in advance. The reason for this mismatch, as I have argued, is that mainstream psychology and its assumed applied science, psychotherapy, has been founded on an object-ontology, treating humankinds as natural kinds (Hacking, 1999). This epistemology (and mismatch) is perpetuated in EBP, creating a situation where the instrumental relations between therapeutic method and symptoms become the focus, at the risk of creating distance and insensitivity towards the client as a subject and person, the lifeworld.

To be recognised as a subject is not only a prerequisite for good results in therapy but also an ethical claim. It means, in principle, to have acquired competence and prerequisites for being able to make one's own choices, take responsibility, have desires and intentions as well as capacity to have judgment when it comes to one's own actions—in other words, capacities that are constitutive of being human—an equal to yourself. That these capacities have been mistrusted, reduced or even taken away, must necessarily be felt as an attack on one's dignity. That is exactly what many psychiatric patients throughout history often have experienced.

It is, of course, necessary for all professional work to objectify and analyse problems and subject matters at stake. Objectifying could be defended and is necessary in some research contexts as well. In clinical work, this objectifying gaze has its limitation. It is a difference between objectifying the client's problems and the client as a person. Exceeding this limit could represent an ethical violation in clinical settings. The Norwegian philosopher Hans Skjervheim has pointed out that our relations to others are primarily ethical, and to reduce or interpret this ethical relation as a technical relation is an 'instrumentalistic mistake' (Skjervheim, 1974). When the person, as such, becomes the target for such an objectifying gaze, putting him in the perspective of a general scheme, it is an attack on his freedom and subjectivity.

In professions, epistemology and ethics are closely intertwined. Applied sciences such as psychiatry, psychology, nursing and social work must, therefore, be considered not only for what they are but also for what they do. Assessing epistemology is not only a matter of what is true or false in a scientific way but also a matter of what is good or bad. In other words, epistemology has ethical consequences. Faced with another human being, whether it is a patient, client or user, the first challenge is not what can be objectified, but to accept that the other is an experiential and interpretive subject, simply a human being like yourself.

Today's operating models with effort-driven financing and employer-designed protocols, government-demanded outcomes and marketised measures of efficiency increase the pressure to standardise practice. EBP fits such a system, with great emphasis on procedures, documentation and 'correct' treatment defined by diagnoses. The challenge is whether it is possible to simultaneously treat the individual as a subject and develop offers adapted to the individual's preferences and the current situation. The danger is that professional ethics can itself be pulled too far into the new accountability paradigm that the professionals become more concerned with securing their back (e.g. using EBP) than doing the good things according to their own professional discretion. In a system where EBP and ethics point in different directions, there is a certain danger that ethics may suffer. Therefore, this reminder is needed: the helper's loyalty must first be to the user rather than to the science. If this imperative has been made too light in the EBP-wave, it must become heavier again; ethics must always come before the evidence.

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Chapter 4
Inherent Risks of the Construction of High-Risk Individuals in Diabetes Treatment and Prevention: An Ethical Challenge

John-Arne Skolbekken

Introduction

When you get diabetes, it changes the rest of your life. It changes who you are. Your body is no longer able to regulate your blood glucose without your conscious effort. In the worst case that of insulin dependent diabetes (aka IDDM or type 1 diabetes), you need to continually monitor your blood glucose level and insert insulin in your body regularly, as well as following a strict regime for what and when you eat. If you fail to do so, the consequences are severe, with premature death looming in the background. Current knowledge about the natural history of type 1 diabetes (T1D) is restricted, thus making it difficult to prevent.

Whereas the above condition will give you symptoms and be perceived as a proper disease, there are other less perceivable and liminal states where you are neither healthy nor sick, but somewhere in between. Familiar examples are asymptomatic conditions like hypertension, hypercholesterolemia, osteoporosis and type 2 diabetes (T2D). These conditions are framed within the modern risk discourse, contributing to 'the converged experience of risk and disease' (Aronowitz, 2009), gradually eliminating the boundary between prevention and treatment. From an ethical point of view, this introduces some new challenges, as public health ethics give priority to what is good for society whereas clinical ethics prioritizes what is good for the individual. The main aim of this chapter is to present a critical analysis of the latter, with particular focus on potential harms of strategies aimed at those that are constructed as being at high risk of developing diabetes.

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Within the risk discourse, there are new subject positions available, described as the risky self (Ogden, 1995) and the empowered vulnerable woman (Dubriwny, 2013). Among lay people these positions are more easily recognised through the dichotomy of healthy and unhealthy citizens, reflecting ways of managing health risks through what is presented as individual lifestyle choices. Implied in this discourse are also strong attributions of individual responsibility, making an individual's health a reflection of personal moral character. Given the multifactorial aetiology of conditions like T2D, it follows that interventions concentrating on only one of them carry the potential for adding burden rather than alleviating it if people are offered interventions that are counterproductive.

This chapter is a continuation of previous work on online risk calculators (Skolbekken, 2019). An important finding from that study is that epidemiologists make strategic choices in order to make public health doable through constructing prediction tools focussing on individuals rather than structural and political factors. In this chapter, I aim to bring this analysis further, by looking at the diabetes situation.

Risk calculators are part of biomedicine's armament for the early detection of disease. Whilst the benefits of early intervention have been praised for centuries, its potential side effects have until recently received far less attention (Hofmann & Skolbekken, 2017). Part of the aim of this chapter is therefore to address some ethical issues inherent in the early detection and diagnosis of T2D and prediabetes. In doing so, I will highlight some potential burdens of the current approach to diabetes, like getting a lifelong diagnosis without ever experiencing a symptomatic disease, being diagnosed through ethnic stereotypes, before looking at how the present individual focus contributes to blaming and shaming of people diagnosed with diabetes, and finally addressing how overlooking structural injustice and poverty may be a major failure of the high-risk approach to diabetes.

In accordance with Burr's (2015) presentation of social constructionism, my aim is to question some of the taken-for-granted knowledge about diabetes today. In doing so, I am by no means denying the biology of diabetes and its dire consequences. Just as (Hedgecoe, 2002, p, 11) 'I am not claiming that diabetes is "whatever we say it is"', but I also acknowledge that part of the problems addressed in this chapter has their roots in the apparent strive for simplicity when facing the complexity and heterogeneity of the thing that is diabetes. In this presentation, we will forget about its ontology and focus on the construction of various diabetes diagnoses, which represent our present social constructions of it. In doing so, I point to the Thomas theorem:

> '. . .if men define situations as real, they are real in their consequences'.'
> Thomas & Thomas (1928, p. 572)

There is no doubt that the present medical description of diabetes results in actions with real consequences in people's lives. In doing so, biomedical researchers are practising what Hacking (2007) calls 'making up people'. People have suffered and died from diabetes since before it was named and recognised as a disease. In this sense diabetes is a natural kind. Through the development of epidemiology and the medical risk discourse medical science creates individuals with a high risk of developing diabetes, first as identifiable groups, then as risky individuals. Such individuals have always been among us, but we did not know them as such until epidemiologists pointed them out to us. By undergoing various tests and communicating with medical expertise, we get to understand ourselves in ways that were not available to our ancestors. This understanding evaded them as the risk discourse was not in place centuries ago. It is now, hence new subject positions are open to us, positions that emerge through social interactions (Burr, 2015).

Traditionally these interactions have involved patients and medical doctors, but according to Hunter (2016), psychologists may now also have an important role to play in the prevention and treatment of diabetes. Whereas this is certainly true, it also becomes pertinent to examine the position taken by psychologists regarding the epistemological and ethical questions addressed in this chapter. This will be done through a critical reading of some of the articles published in a recent theme issue of American Psychologist, an issue covering a lot of research whilst simultaneously serving as an advertisement for this profession's capabilities.

The Diabetes Epidemic

Diabetes is characterised as one of the biggest threats to people's health globally, giving cause for alarm. It is argued that the T2D epidemic is the biggest in history, affecting 415 million people globally (Zimmet, 2017). The majority of cases are found in India (80–90 million) and China (120 million), but no country is unaffected by this situation. Part of the reason behind the alarm is the fact that these numbers are well above earlier projections made by the International Diabetes Federation and the WHO, respectively. Another reason is the observation that the numbers have doubled over the past decades and are expected to increase by another 200 million cases in the next couple of decades (Zimmet et al., 2016). What the exact numbers are, is hard to tell, as differences of opinion exist over what constitutes the appropriate diagnostic criteria for diabetes, leading to discrepancies in prevalence numbers. To understand this better, we move to a description of diabetes mellitus.

Diabetes Mellitus

It is commonly accepted that diabetes is not one disease covered by one diagnosis, but a range of conditions. This was indicated almost a century ago, when Sir John Rose Bradford (some years before 1938) presented his definition:

> 'Diabetes is not an entity, but a clinical label attached to a number of different conditions with varied origin, different morbid anatomy, and liable to follow different courses.' (Embleton, 1938, p. 1184).

More recent contributions have not proved Bradford wrong, but have offered updates like these:

> ‘Diabetes mellitus is a syndrome currently recognized and classified as a group of diseases characterised by signs and symptoms of hyperglycaemia’ (Zimmet et al., 2016).
>
> “Diabetes mellitus is a complex metabolic disorder whose main clinical and diagnostic feature is hyperglycaemia” (Zaccardi et al., 2016).
>
> ‘Diabetes comprises many disorders characterized by hyperglycaemia” (WHO, 2019).

In a normal and disease-free body, the level of blood glucose is regulated by release of insulin from the pancreas into the bloodstream. T1D occurs when this metabolic process fails due to autoimmune destruction of insulin producing pancreatic beta-cells, leading to an absolute insulin deficiency and the need for insulin treatment. T2D is characterised by insulin resistance and/or a relative insulin deficit, leading to elevated blood sugar. Whereas T1D will be detected through symptoms, symptoms of T2D may be absent or vague early in the course of the disease. Therefore, T2D can go undetected for many years. It is this condition that is by far the most common form of diabetes, and the one that is contributing the most to the epidemic mentioned above.

Technology allowing, the detection of T2D thus became vital to enable medical intervention before the manifestation of disease. This is where the definition of hyperglycaemia is paramount. According to the WHO (2019), there are three types of testing—fasting plasma glucose, post load plasma glucose, and measurement of HbA1c. The outcomes of these tests are problematic in the sense that their outcomes will differ, leading to different people fulfilling the diagnostic criteria. Furthermore, the quality of these measurements is debatable, and there is a weighing of accuracy vs. resources needed to perform the diagnostic test. The WHO thus acknowledges that their criteria is a compromise, giving priority ‘to clinical care over aetio-pathology and epidemiology’ (2019, p. 3).

To further understand what is at play in the detection of T2D, we also need to take a step back to the middle of the twentieth century when developments in pharmacology contributed to the definition of the disease (Greene, 2007). This happened with the introduction of the drug Orinase, originally introduced as an oral alternative to insulin injections. It did not have the qualities to regulate diabetes as well as insulin in young patients but did the job for older ones. To ensure that Orinase was recognised for this accomplishment, it became pertinent to its producers to gain recognition for its effect on patients with a different type of diabetes than the one previously known. This diabetes was a more hidden form than T1D. To make it identifiable, pharmaceutical companies provided doctors with screening devices for sugar in the urine. Having enabled the identification of this hidden diabetes, they acknowledged facing a ‘very complex psychological problem’ (p. 103)—how to convince people who do not feel sick that they may be in need of a medical intervention? In the medical enterprise of making up people, this was one of the first successes in constructing an at-risk identity based on statistical numbers to create a new diagnosis.

This was also an early example of what is described as the pathologisation of normality (Skolbekken, 2008). This is related to the practice of identifying normal bodily processes involving blood pressure, blood cholesterol, bone mass and blood glucose as pathological through making risk-based cut-offs on normal distributions. The definition of hyperglycaemia is thus the outcome of a process which has been repeated numerous times since its original version, constantly widening the inclusion criteria, defining larger and larger proportions of what has hitherto been defined as healthy populations as being in need of medical assistance. The wisdom of this is under debate, including its contribution to the diabetes epidemic.

Prediabetes and the Risk of Overdiagnosis

The ethical challenges emerging through the arbitrary definition of T2D are no less when an even earlier diagnosis is constructed through the concept of prediabetes:

> ‘If the symptomless or pre-diabetic state could be recognized, it would constitute the best material on which to test the effect of treatment directed towards improving the diabetic syndrome’ (Embleton, 1938, p. 1185).

It is reasonable to assume that this notion of prediabetes included the condition we now know as T2D. Presently, however, prediabetes is ‘defined as blood glucose concentrations higher than normal, but lower than diabetes thresholds, [it] is a high-risk state for diabetes development’ (Tabak et al., 2012, p. 2279). As for T2D, these thresholds are not naturally given, but are the outcome of negotiations among experts, who decide yet another cut-off on the bell curve. Reflecting their arbitrariness, these cut-offs vary around the world, with the American Diabetes Association leading the way of including the most extensive part of the population into this diagnostic category.

As communicating risk scores is proven to be a demanding task for both general practitioners (GPs) and their patients, defining them as diseases in their own right is found to make their jobs easier. In a Danish interview study, the diagnosis of prediabetes was described metaphorically as a weapon, making the threat to patients’ health more real (Hindhede, 2014; Hindhede & Aagaard-Hansen, 2015). This is similar to what has been found with respect to patients’ acceptance of taking medicines to lower their cholesterol, based on the transformation of a future health risk into a current health problem by means of providing a diagnosis (Polak, 2016). The prediabetes diagnosis contributed to the patients’ acceptance of the overall narrative of their own responsibility for their pathologized situation, as both the cause and the solution to the health problem. It increased their willingness to change lifestyle, albeit not all the patients lowered their glucose level as a consequence of the changes. This points to part of the problem arising when a condition with a multifactorial aetiology is approached in a reductionistic fashion through the lens of the lifestyle as individual choice discourse.

Another problem with the prediabetes diagnosis is that it indicates a stage in a process that will unavoidably lead to diabetes if left unattended. As demonstrated in a meta-analysis by Morris et al. (2013), just as many people diagnosed as having prediabetes return to levels of normal blood glucose as do develop diabetes. In other words, the identification of people with high risk of developing diabetes is uncertain as knowledge at the individual level.

This implies that prediabetes carries a potential for overdiagnosis, meaning 'the diagnosis of a condition that, if unrecognized, would not cause symptoms or harm a patient during his or her lifetime...' (Kale & Korenstein, 2018). Overdiagnosis reflects a lack of knowledge about the development of a disease at the individual level, which is hidden in the statistics of evidence-based medicine. It is not a problem just with diabetes, as the heated debate over cancer screening bears witness of.

The early intervention strategy is thus not without its critics, like the one presented by Yudkin and Montori (2014). Their major concern is that the number of people with prediabetes has risen dramatically with recent definitions, putting half the population of China into the intervention group if the American diagnostic criteria were to be applied. A further challenge is related to the previously mentioned lack of consensus as to how to actually measure prediabetes. Different blood glucose measurement techniques lead to a discrepancy as to whom actually gets the diagnosis, making the diagnostic process something of a lottery.

Despite such criticism, the idea of early interventions still stands strong in preventive medicine. This is demonstrated by what is described as the surge in publications on early detection (Hofmann & Skolbekken, 2017). The number of these publications is increasing dramatically in many medical specialities. A notable feature of this literature is its strong focus on the benefits of early intervention compared to the harms and burdens involved. The appeal of early interventions makes good sense from a clinical point of view, based on a notion of a point of no return in a detrimental disease process. If this notion is inaccurate, as indicated by the overdiagnosis literature, the outcome may be a number of individuals carrying the burden of adapting to the subject position of being the carrier of a chronic disease without actually having one.

In psychology, criticism has been raised at the limitations of the biomedical model, portrayed as increased testing and biomedical interventions as well as lack of attention to behaviour and social context (Johnson & Marrero, 2016). Simultaneously, however, the prevalence of prediabetes among Americans is presented as a major argument for psychological interventions, without any mention of its inherent potential for overdiagnosis and subsequent overtreatment. This indicates that psychologists may also do well to reflect closer on both sides of the coin that is prediabetes.

High-Risk Individuals: The Construction of Standardised Humans

As noticed, extensive testing of asymptomatic individuals is a central element of the biomedical approach to prediabetes and T2D (Johnson & Marrero, 2016). The issues mentioned above have hitherto had little effect in terms of sobering the enthusiasm for early identification of diabetes. If anything, the enthusiasts have taken this one step further in an attempt to identify high-risk individuals without involving blood glucose testing. Such testing is time consuming and costly, a fact which in particular influences the ability of low-income countries to identify diabetes early. The hope attached to this testing is the belief in the health-care systems' ability to help the identified individuals in successfully changing their lifestyle, something which has been proven to be effective in interventions based on randomised controlled trials (RCTs) (West et al., 2016).

For the sake of putting things in perspective, it is important to note that such interventions have not been the only ones tried out. In the high day of eugenics, sterilisation of people with diabetes was among the preventive strategies being discussed (Tuchmann, 2020). Among the candidate groups for this intervention were Jews, who late in the nineteenth century and for most of the first half of the twentieth century were seen as being at high risk of getting diabetes, so much so that diabetes at the time was described as 'Judenkrankheit' (Ibid).

Among the supporters of early identification of high-risk populations and individuals, prediction tools are presented as reliable aids available to those that want to get an estimate of the incidence of diabetes in a population as a basis for prevention and control (Rosella et al., 2012). The appeal of this idea has contributed to the construction of a vast number of risk calculators in recent decades. An important feature of these tools is the sorting of humans into two or three standardised categories according to their calculated risk status.

Many of these instruments were thoroughly reviewed a decade ago by Noble et al. (2011). Despite stating that they 'provide good but not perfect estimate of the chance of an adult developing diabetes in the medium term future' (Noble et al., 2011, p. 5), the evaluation also listed a number of limitations making the outcome of a large-scale implementation uncertain. A point worth noting is that these instruments fail to meet some of the criteria for population screening established by the WHO half a century ago (Wilson & Jungner, 1968). Among these are the accuracy of diagnosis generated (false positives), knowledge of the natural history of the disease (from latent to declared disease) and the balancing of costs and benefits of case finding which is often seen as a problem with an opportunistic screening compared to an organised population screening.

In more recent versions of screening criteria, making sure that people are offered screening as an informed choice is among the criteria added (Andermann et al., 2008). This implies that individuals offered to have their diabetes risk calculated should be informed of both the benefits and harms involved, thus protecting their autonomy. Judging by the information presented on websites where risk calculators are freely available online, balanced information is not offered (Skolbekken, 2019). Rather, the providers protect themselves through disclaimers, typically refraining any responsibility for the information generated.

Constructing High-Risk Individuals through Ethnical Stereotypes

Many of the diabetes risk calculators are constructed for use in one particular population, typically a nation. A noticeable variation among the calculators is between those requiring that the person identify as belonging to an ethnic group and those that do not. This mirrors how the notion of ethnicity has become a significant background variable in the epidemiology of some nations.

Throughout history, there has been shifting observations in who the populations at high risk of diabetes are and what their characteristics are (Tuchmann, 2020). The Jews have already been mentioned. In the past, people in biomedicine also believed that there were groups of humans that were immune to diabetes. For a long time both Afro Americans and Native Americans were believed to be immune, explained by reference to what was then described as the primitive nature of their nervous systems. This changed over time, as these groups are now seen as among those with the highest risk of getting diabetes.

Pointing out these groups for attention thus comes with a lot of baggage. Ethnicity and race are still highly debatable variables in medicine (and elsewhere). Just recently, the New England Journal of Medicine published an article warning that race-adjusted algorithms as a tool for perpetuating or amplifying health inequities (Vyas et al., 2020). It is not just by accident that calculators including ethnicity as a variable are to be found in countries like Australia, Canada, the UK and the USA.

Addressing the issue, Bhopal (2006) made an appeal to responsible use of the concepts of race and ethnicity in both epidemiology and public health. Acknowledging inherent problems, he also saw it as problematic to remove them altogether. This has later been resounded by Liz (2019), arguing that ignoring the diversities imbedded in these categorisations would be even more problematic than not including them, thus reflecting an ethical dilemma.

If the countries including race and ethnicity in their epidemiology, and Bhopal and Liz are right, then maybe the majority of European countries are wrong? A review on the research on the prevalence of T2D among ethnic minorities in Europe demonstrated that this is limited to Nederland (4), the Scandinavian countries (Denmark 1 Norway 2, Sweden 4) and the UK (9) (Meeks et al., 2016). Classification in the non-British studies is based on geographical origin of immigrants, which is slightly different from other notions of ethnicity.

Latin America is another part of the world with a diverse and mixed population, where what is regarded as properly validated calculators are limited to a few countries (Carillo-Larco et al., 2019). Believing that more calculators are needed, these researchers see the solution for Latin America as one calculator for the whole continent or country-specific calculators. The idea of ethnic specific calculators for the southern part of America is thus not on the table. This is quite different from how people from the south are constructed in the US, where they are labelled as Hispanics (Liz, 2019), a category that emerged in the 1980 US census (Tuchmann, 2020).

A more fruitful approach may well be to acknowledge that how these studies are situated in their respective contexts are more important than if ethnicity is an included variable or not. In this sense, much depends on whether the use of results in identifying high-risk populations and individuals as those in need of help or as those posing a threat to society. Whatever the outcome, it is important to acknowledge that inclusion of such variables may create, reify, perpetuate and amplify stereotypes rather than serve to improve people's health.

Bhopal (2006) also offered definitions of ethnicity and race, but in vain. His definition of ethnicity clearly places it within a cultural frame, much like how anthropologists use the term (Banks, 1996). In the risk calculators, however, ethnicity is listed among the variables that cannot be influenced by health behaviour, thus indicating a more stable biological entity, likely in the form of genes. Although a genetic influence on the development of diabetes long has been anticipated, little substantial evidence has surfaced so far. The existence of a "thrifty gene" has been a source of much debate since its conceptual introduction in 1962 but has not proved very productive in explaining differences in prevalence of diabetes among populations (Tuchmann, 2020).

Looking at more recent history, a look at the changes that have been made in ethnic categories may be enlightening. In a review of ethnic inequalities in health among people living in the UK, various categorisations of groups of immigrants were used (Smith et al., 2000). As can be seen in the left column of Table 4.1, country of birth was used for mortality, albeit some categories were parts of a continent rather than countries.

For T2D, the options were limited to four categories, as demonstrated in the next column. Decades later, as can be seen in the third column, the categorisations of the

Table 4.1 Ethnicity in the UK 1991–2020

Mortality according to country of birth	Type 2 diabetes	Diabetes UK calculator input	Diabetes UK calculator output
Caribbean	European	South Asian	White
West/South Africa	South Asian	Black	Others
East Africa	African-Caribbean	Chinese	
India	Chinese	Mixed ethnicity	
Pakistan		White	
Bangladesh		None of these	
Scotland			
Ireland			

Column 1 and 2 are based on (Smith et al., 2000), column 3 and 4 are based on https://riskscore.diabetes.org.uk/start

Diabetes UK demonstrate a further change. The most remarkable thing here is how these categories are further reduced to encompass only whites and others when the diabetes risk is communicated. In the context of diabetes, the construction of the category of South Asian is the most interesting one, meshing the many people of Bangladesh, India and Pakistan into one large ethnic group. This is quite contrary to the vast ethnic diversity in India that has been pointed out by Indian researchers (Unnikrishnan et al., 2016).

On a more personal level, Keval (2016, p. 65) shares his experience:

> 'When I present myself to my GP surgery, I appear as a mid-40s male, British South Asian in origin. The advice I am automatically given, regardless of any personal, socio-economic, material, biographical, or sociocultural context, is that I am at a higher risk of acquiring diabetes than another mid-40s male with an identical profile, who happens to be classified as "White"'.

This experience may on the one hand be seen as founded in epidemiological research, where the evidence base for categorising South Asians as having elevated risk for diabetes is strong. At the same time, his experience demonstrates how this evidence is reframed into a stereotype in the individual clinical encounter. This is similar to what can be found in other ethnic groups identified as high-risk individuals. It is also the experience of people categorised as obese, a point that we shall return to below.

The arbitrariness of the epidemiological construction of statistical persons is clearest in the following statement from the development of the AusDrisk calculator (Chen et al., 2010, p. 199):

> 'Therefore, people of southern European, Asian, Aboriginal and Torres Strait Islander and Pacific Islander background were combined into a single, high risk ethnic group'

In the present version of the calculator (checked online 13.11.2020), ethnicity is scored on two sub-questions, reflecting a reshuffling of the groups compared to the original version. This difference does not, however, change the importance attributed to ethnicity in the calculator.

The Burden of Making the Development of Diabetes an Individual Responsibility

As noted at the beginning of this text, the present risk discourse is based on the notion of health risks as the outcome of individually chosen lifestyles, making attributions of individual responsibility tempting. Not surprisingly, the outcome of such attributions may be the shaming and blaming of people with diabetes. Recently, it has been reported that character flaw/failure of personal responsibility and burdening of the health-care system are among the most frequently reported stigma among predominantly white Americans with T1D and T2D (Liu et al., 2017).

Such experiences are not exclusive to Americans, however, as demonstrated by a review of the international literature (Schabert et al., 2013). The types of stigma differ across cultures, but the resulting stereotypes contribute to negative psychological well-being and concealment efforts affecting self-care, and eventually clinical outcomes. Matters are not helped by the fact that various groups of health professionals contribute to the stigmatization of people who are defined as overweight and obese (Puhl et al., 2016). In recent decades, overweight and obesity have been singled out for special attention among the risk factors for T2D, bordering on monocausality, hence the introduction of the term ‘diabesity’ (McNaughton, 2013). As a consequence, professionals’ attitudes towards people with obesity also influence diabetes interventions.

The strong belief in individual responsibility for diabetes and strong focus on obesity is also reflected in the framing of RCTs for lifestyle interventions against T2D (Bombak et al., 2020), which is the backbone of the legitimation for psychological lifestyle interventions, as those presented by West et al. (2016). Beyond optimistic claims of evidence-based interventions, it is hard to find reflections on the resources needed to live a life according to the most intense of these interventions. Not resources in the form of cognitive ability, but more in the terms of time and money. This example of planned behaviour from a five-step program may serve as an illustration—‘Each Monday I will bring sensible, ready to eat snacks to the office and keep in my desk drawer and plan to walk with my coworker during break’ (Ibid, p. 622). Whereas there is little reason to doubt that this is good strategy for some, there are certainly individuals who are not in a position to make the choices taken for granted in this plan.

Seen from a slightly different perspective in psychology, Roberto (2020) explains how structural factors influence our daily lives in what she calls ‘modern food environments’, exploiting our tendency for present-biased preferences and planning fallacy, contributing to unhealthy food choices. Her conclusion is that lasting changes can only be achieved through changing these environments that are part of the larger construct of ‘obesogenic’ environments. In this sense, the dominant individual approach to diabetes may also be seen as the outcome of a discourse mirroring the fundamental attribution error.

Overlooking Structural Injustice and Poverty

The appeal of the individual approach should come as no surprise, given its foundation in the ideals of individual liberty and the apparent backing it has in scientific evidence. It is, however, worth remembering that this evidence is stripped of context through the overlooking of the many factors outside individual control that are crucial to people’s health. The influence of social determinants on health and diabetes has very recently been reviewed by Hill-Briggs et al. (2021), demonstrating that in the US, factors such as socioeconomic status, neighbourhood and physical environment, food environment and social context have considerable impact on the risk of getting T2D.

This situation is just one example of what has been described as the health gap, reflecting that we are living in a world where the resources are unequally distributed (Marmot, 2015). Addressing the issue of personal responsibility for one's own health, Marmot stresses that people's responsibility is limited by the factors that they cannot control, making an appeal for greater interest in the causes of the causes. Among these may also be the coproduction of genes and environment in an epigenetic intergenerational model, according to which diabetes may develop over generations related to the individuals' history in utero (Chaufan, 2008; Zimmet, 2017).

Appreciating the potentially negative outcomes of ignoring social forces when approaching individual patients, an appeal has been made for raised attention to them not only in public health but also in physicians' clinical practice (Holmes et al., 2020). There is good reason to believe that this is an appeal that may be extended to any health-care profession.

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Chapter 5
The Relationship Between Ethics and Ontology in Researching Suicide

Katrina Jaworski

Introduction

The aim of this chapter is to examine the impact and influence of research ethics beyond the practical concerns of university human research ethics committees in the context of researching sensitive topics such as suicide. Indeed, researching sensitive topics more broadly, and suicide in particular, is hard work on a number of levels. While difficult to define precisely, sensitive topics are usually associated with traumatic topics, or topics perceived as being drenched with feelings of dread, fear, anxiety and shame. With elicitation of emotional distress comes the risk of harming the participants, and by extension, researchers (Dempsey et al., 2016; Elmir et al., 2011). Nevertheless, existing research literature in the field of qualitative methodologies nowadays argues that researching sensitive topics is both valuable and important and thus should not be avoided. This is because vulnerable people are given the opportunity to have their experiences taken seriously, be recognised as legitimate sources of knowledge, feel empowered and experience catharsis and a sense of relief that comes from being heard (Corbin & Morse, 2003; Elmir et al., 2011). For these reasons, methods such as interviewing, be it semi-structured, unstructured or narrative, are considered to be the most appropriate ways of collecting data on sensitive topics (Elam & Fenton, 2003; Elmir et al., 2011).

While appropriate, interviewing people with traumatic lived experiences is challenging. Researchers need to be highly skilled at yielding meaningful data while simultaneously enabling participants to feel safe (Corbin & Morse, 2003; Dempsey et al., 2016; Elmir et al., 2011; Hewitt, 2007; Liamputtong, 2007). Successful interviewing requires meticulous planning, a thoughtful interview schedule, empathic listening, sensitivity and very good rapport-building skills (Clarke, 2006;

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Corbin & Morse, 2003; Dempsey et al., 2016; Elmir et al., 2011). Rapport building is essential towards minimising power imbalances between researchers and participants (Clarke, 2006; Dickson-Swift et al., 2007; Gemignani, 2011; Elmir et al., 2011). Critical reflexivity is also crucial not only in regard to researchers remaining self-aware but also because they need to take care of themselves. Interviewing can be difficult because the content might be difficult to bear witness to, and because researchers may have strong feelings about, or lived experiences associated with the phenomena under investigation (Dickson-Swift et al., 2005; Dickson-Swift et al., 2006; Elmir et al., 2011; Johnson & Macleod-Clarke, 2003; Rowling, 1999). As Dickson-Swift et al. (2007, p. 342) write,

> In listening to a person's account of their life or their illness experience, we are effectively opening up in an embodied and personal way to the suffering of that other person that may give us a heightened sense of our own mortality and vulnerability.

Thus, as Stanley and Wise (1993) suggest, researchers need to be open to and prepared for showing their vulnerabilities. Keeping a reflective journal or diary is crucial because it documents a conversation researchers might need to have with themselves, which includes reflecting on emotional reactions, problems encountered during an interview and emerging ideas (Clarke, 2006; Johnson & Macleod-Clarke, 2003; Rowling, 1999).

Gaining ethical clearance from institutional human ethics review committees is part of being a skilled qualitative interviewer. Safety of participants, participant consent and protection of confidentiality and anonymity are primary concerns in qualitative research projects (Holland, 2007; Juritzen et al., 2011). These concerns are rooted in respect for individual autonomy and respect for privacy (Guillemin & Gillman, 2004). While exercising benevolence is crucial, as Juritzen et al. (2011) discuss, this exercise is not without its problems. Human ethics review committees' views are often science driven and therefore more suited for biomedical and quantitative studies (Annas, 1991; Holland, 2007; Juritzen et al., 2011; Schrag, 2011; Vadeboncoeur et al., 2016). Furthermore, the process of gaining clearance is often bureaucratic: a process through which researchers become more concerned with gaining clearance rather than what is appropriate ethical practice (Juritzen et al., 2011; Monaghan et al., 2003). As Annas (1991, p. 19) aptly puts, 'the term "ethics" is inappropriate, and the committee should be called "risk management", or a "liability control" committee'. This is because the principal focus of human ethics review committees is managing fear and risk in the interest of protecting not only the participants but also the interests of the given institution in which research is conducted (Lindorff, 2010; McAreavey & Muir, 2011).

Given that it belongs to the category of a sensitive topic, similar issues feature in existing literature on suicide research. While quantitative studies continue to dominate the field of suicidology, or the field committed to the study of suicide, qualitative research is finally making its mark on the debates concerning research designs and their practices. When qualitative interviewing in suicide research is discussed, much of the attention remains on informed consent, building of rapport and the vulnerability of participants and researchers more broadly, focusing on their emotions and feelings in particular (Boden, 2018; Boden et al., 2015; Mugisha et al., 2011). Boden et al. (2015) argue that feelings and emotions are crucial in qualitative interviewing. They write,

> In all cases, feelings resonate in our bodies *and* permeate others, events, spaces and objects; they tell us about our relationship with the world. . . . It is precisely because feelings provide us with knowledge about the nuanced meanings in our encounters (they are *epistemically* important), that feelings are also *ethically* important. (Boden et al., 2015, p. 1079, original emphasis)

In this sense, researchers need to be technically *and* emotionally skilled. Critical reflexivity is part of this skill set, for it involves exploring subjective and intersubjective elements of interviewing to make sure that the quality of the analysis is not compromised (Finlay, 2002). All of this requires courage, because of the need to 'open ourselves more fully to *being with* our participants and their stories, even when this is painful and challenging' (Boden, 2018, p. 54, original emphasis).

Despite the plethora of research on the topic of suicide, very little attention has been given to ethical issues facing suicide researchers (Hom et al., 2017; Andriessen et al., 2019a, 2019b). In analysing the experiences of suicide researchers with human ethics review committees, studies report potential harm to participants and researchers' responsibilities to participants as the most common areas of concern (Andriessen et al., 2019a, 2019b; Gibson et al., 2012; Lakeman & Fitzgerald, 2009a, 2009b; Mishara & Weisstub, 2004; Moore et al., 2013). Responsibilities towards participants include maintaining confidentiality and participant anonymity and providing support (Biddle et al., 2013; Johnson, 2007; Lakeman & Fitzgerald, 2009a; Mishara & Weisstub, 2004). In other words, the risk of a participant suiciding remains at the forefront of the process of gaining ethical clearance.

As important as research skills and ethics are in the context of researching sensitive topics broadly, and suicide in particular, most of the existing research literature frames ethics as procedural or pragmatic. When researchers explain 'ethics as process' or 'ethics in practice', such framings do not move beyond discussing everyday ethical issues that researchers must face in the doing of research (Guillemin & Gillman, 2004; Ramcharan & Cutcliffe, 2002). What is yet to be debated properly is the issue of ethics beyond the practical concerns of university or institutional research ethics committees. That is, we are yet to understand the relationship between research ethics and ontology, where the former is more than a research code of conduct and the latter moves past assuming that who we are as researchers is distinctly separate from what we research. While recent discussions do acknowledge that suicide researchers are implicated in what they research (Boden, 2018; Boden et al., 2015), such discussion does not extend past the role of feelings and critical reflexivity in research ethics.

In response, the aim of this chapter is to examine the relationship between ethics and ontology in research practice by focusing on my experiences of interviewing queer young people about their familiarity with suicide. These experiences are based on a qualitative pilot study, which drew on the unstructured interview technique. Inspired by the work of Judith Butler, Emmanuel Levinas, Michel Foucault and

Donald W. Winnicott, I demonstrate that research ethics in the process of unstructured interviewing are about ontology as much as they are about practical issues. I also will demonstrate that researchers as much as the researched are implicated in the relationship between research ethics and ontology—an implication that offers hope rather than just a sense of psychological relief and catharsis. In this sense, ethics in research practices are never outside the company of those we research.

Sexuality, Identity and Queer Young People's Experiences with Suicide

Between 2012 and 2017, I conducted a pilot study based on an exploratory and descriptive qualitative approach to investigate the relationship between sexuality and identity in queer young people's experiences of suicide. This methodology was selected to collect in-depth and situated accounts of queer[1] young people's experiences with suicide, based on their own perspectives (Denzin & Lincoln, 2018). To collect the data, I deployed the unstructured interview technique, because it enables the participants to have control over the interview process (Corbin & Morse, 2003; Fontana & Prokos, 2007). Alongside aiming to explore the relationship between sexuality and identity, the second aim was to test the appropriateness of the unstructured interview method, especially since qualitative studies of queer youth suicide based on this method were rare at the time. The study was approved by the Human Research Ethics Committee (HREC) at the University of South Australia.

I recruited participants through university notice boards, toilets and a local Rainbow Club.[2] I used purposive sampling to recruit participants on the basis of them having 'particular characteristics which enable…detailed exploration and understandings of issues central to the project' (Ritchie et al., 2003, p. 78). I interviewed 10 information-rich participants, who were between 18 and 25 years of age, self-identified as queer, came from various cultural backgrounds and either contemplated or attempted suicide in the past. Two of the young people self-identified as cis-gender gay men; four as lesbian women; one as cis-gender woman attracted to other cis-gender women; one as a trans man; one as a non-binary bisexual; and one as a bisexual woman.[3]

The interviews were held at the university campus I work, in a location considered private and safe. From the moment we sat down, I wanted to be open and honest

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[1] This chapter "queer" is a flexible and inclusive umbrella term describing a range of sexual identities such as lesbian, gay, bisexual, transgender, transgender and intersex (McCann & Monaghan, 2020; Sullivan, 2003).

[2] Rainbow Clubs are usually located on university campuses in Australia. They are clubs often run by queer students, and aim to provide an inclusive, safe, fun and engaging campus environment for LGBTQI students.

[3] In wanting to avoid the possibility of the term, "queer," becoming a homogenising term, I asked the participants to tell me how they defined or worded their identities. These are their words.

with the participants to acknowledge their courage to share their stories with me. Once the consent form was signed and freedom to withdraw at any time communicated, each interview began with me explaining the reasons for the study, why I personally cared about the topic and why I decided to use the unstructured interview technique. I also said I had questions to guide the conversation, but this was only in case they wanted to start the interview. I assured each participant had complete control of where our conversation would take us. As requested by the University's HREC, the 'just-in-case' interview schedule was:

1. In order for me to know you a bit better, tell me about yourself?
2. Tell me about how you came to know your sexuality: how did you adjust and negotiate it?
3. What happened in regard to suicide?
4. How did you turn away from suicide, what made things okay?
5. How would your friends describe who you are?
6. What is the best part about being queer?

Even when I did not stick to the questions, the first half of each interview focused on how the young people discovered their identities and they came to experience suicide; the second half focused on survival, their identities and lives in the present. Interviews lasted between 40 minutes and two and a half hours. All interviews were digitally recorded and transcribed verbatim to ensure the accuracy of data interpretation (Liamputtong, 2009; Patton, 2002). After each interview, I would digitally record my own thoughts, feelings and responses to what I heard. This reflexive journaling helped to identify what stood out about each interview. I would sometimes record emerging ideas, but this depended on how exhausted I felt at the time.

Following a thematic method of analysis, defined as 'identifying, analysing and reporting patterns (themes) within data' (Braun & Clarke, 2006, p. 79), I initially read and re-read interview transcripts for a sense of the 'whole'. I worked on each interview transcript at least twice, with time apart between readings to maximise interpretive rigour. This process enabled me to identify categories and themes that recurred in the data (Gibbs, 2012). I used thematic analysis because, as Braun and Clarke (2006, p. 79) state, it 'minimally organizes and describes your data set in (rich) detail'. This was important in making sure the analysis captured the voices of young people as much as possible, knowing their voices were now bound to my interpretive lenses. Apart from a few of the participants, I was unable to seek feedback on my analysis.

Even though the outcome of the data analysis is not the focus of this chapter, it is worth describing some aspects. Most of the young people I interviewed experienced serious forms of bullying and homophobia in high school, lack of support from teachers and counsellors, rejection by peers and family and when not completely rejected, family members did not know how to respond to their coming out, or their ways of being queer. Two participants experienced physical, emotional and psychological abuse, one of which moved out of home in their late teenage years because of the physical abuse. Some experienced homophobia in the workplace. Others had a terrible time with the mental health system, because they were not taken seriously enough. Others found it hard to be on anti-depressants because they wanted to know when they would get better, which seemed unpredictable. Even when some participants were accepted, their peers still demanded them to be queer in stereotypical ways. Some found this demand frustrating because they were still working out their sense of queerness. And of course, the young people talked about their bodies—how they understood their embodiment and what physically happened to their bodies when they turned to suicide. Trust in authority figures and parents made things better, as did the refusal to let go, a strong sense of justice and a deep desire to prove themselves academically. Some fell in love and formed strong bonds and others developed a strong sense of kinship with accepting family members and friends. Others discovered the joys of queer sex. Put together, these reasons offered the participants a sense of having a future in which things would be different rather than just better.

Gaining Ethical Clearance

In Australia, research across universities, government departments and other funding organisations is guided by The National Health and Medical Council (NHMRC) *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*, which consists of guidelines produced in accordance with the National Health and Medical Research Council Act 1992 (National Health and Medical Council, 2018). The statement identifies four core values: (a) respect for human beings (which includes protecting anonymity), (b) research merit and integrity, (c) justice (benefits and burdens of research and procedural justice) and (d) beneficence (potential harm and benefits of research to participants and wider community). The *National Statement* further specifies that the responsibility for the ethical design and conduct of human research is exercised at various levels, including researchers, ethical committees, funding organisations and government departments (National Health and Medical Council, 2018). Once the funding for the pilot study was approved, I submitted the application for ethics clearance. I expected to undergo a full review, or Ethical Review Level 3 of HREC at my university due to the topic of the study.

The decision I received for my ethical clearance application was ‘approved subject to’. In a nutshell, the risk management/minimisation strategies were not sufficient. I had to ensure a more immediate access to specialist professional counselling and care for vulnerable participants in the event they displayed suicidal or self-harming tendencies. I had to improve strategies of protecting my own safety and provide clearer risk management strategies if participants displayed suicidal tendencies or other risky behaviours or disclosed information which indicated that they were ‘at-risk’ of suicide during the interviews. I was invited to attend a meeting with the committee to discuss issues related to safety aspects of the study. This invitation was part of the final approval process.

Without going into too much detail, the concerns were addressed as follows. I added two extra sample characteristics: interview only participants who did not experience suicidal ideation or attempts for at least 12–18 months and were not under psychiatric care. I reviewed my risk management/minimisation strategies by ensuring all interviews would take place on-campus and in person only. I consulted with the on-campus security team to gain their approval of the protocol I would follow with each interview (check in before and after each interview), to learn about campus emergency procedures and passive use of space during interviews. I consulted with the on-campus psychology clinic to establish what services could be used in case of an emergency. I provided a 'just-in-case' interview schedule, or a set of questions in the event a participant requested me to ask questions. I decided against the use of the snowballing technique to recruit participants due to privacy issues. I agreed not to employ professional transcription services, and instead a research assistant who would sign a confidentiality statement and transcribe all interviews on-campus in my office. Overall, it took 8 months to gain ethical clearance. Meeting the transcription requirement severely depleted my funding as research assistants are less skilled than professional transcribers and take a lot longer to transcribe interviews. While the process of gaining ethical clearance was immensely useful, it did not emotionally and ethically prepare me as a researcher for what was to come.

Interviewing the Suicidal Other

As a researcher who passionately cares about researching suicide and has been writing on the topic for over 20 years, I found the interviews incredibly profound, deeply moving and sometimes traumatic. This was because of the honesty between myself and the participants, raw feelings and the tears, or the fact that I was keeping company with some young people who were yet to come out of the closet at the time, because of the threat of family violence. I knew from the start that, as Boden (2018, p. 59) writes in relation to her experiences of interviewing survivors of suicide attempts, opening myself up 'to the other means being willing to acknowledge and sit with their felt experiences'. I had to *be with* the participants 'and their stories, even when this . . .[was] painful and challenging' (Boden, 2018, p. 54). Furthermore, the interviews were challenging to face, because in some of the interviews the participants did most of the talking, and this talking contained viscerally distressing histories. Still further, in my mind I saw courage in practice. I find it difficult to put this into words other than to say that something kept unfolding throughout each interview, as each participant revealed something more of themselves. I bore witness to perseverance in the face of adversity. Each and every time this happened, I was reminded that my experience in qualitative interviewing and the code of research ethics got me to the interview stage, and the rest was uncertain, dependent on the encounters between myself and the young people.

Let me offer an example of what I have described above. I interviewed Beckett in 2014. At the time, Beckett (pseudonym) was in her 20s, completing a postgraduate degree in creative arts. Beckett grew up in rural Australia and came from a well-educated family. In her late teens, Beckett came to study media arts at the university where I work. The interview took two and a half hours and resulted in a 60-page transcript. I literally asked Beckett one question at the beginning of the interview, namely, 'tell me about yourself', after which she did most of the talking. As an interviewer, I was completely transfixed, listening closely to what she was saying. Her speech was intense, each sentence pouring out after the other, describing in detail situation after situation. Such descriptions did not offer a linear narrative. Rather, Beckett's narrative branched off into different directions, only to loop back to what she wanted to emphasise or expand upon. Thus, what I describe below may come across as linear when in fact it is not. Due to the length of the interview, I can only offer portions of what was recorded and transcribed.

Beckett self-identified as a 'a cis-gendered female woman, who is attracted to other cis-gendered female women'. Beckett also referred to her identity as gay and as 'a queer woman' throughout the interview, because 'the term lesbian does not actually fit'. Starting from when she was a child, Beckett struggled to fit in the rural town she grew up. This was despite being an intelligent, active, creative, tactile child who loved making things and was loved by her family, including her grandparents. Beckett "did not have dollies and was very much a tomboy'. Until the age of 10 or so, most of her friends were boys, because 'we got to fight, and I really liked fighting'. At school, Beckett was bullied, which made her wet her bed at night until she was 12 years old. Later on, she was perceived as very smart and took accelerated classes in high school for subjects such as English. Nevertheless, by year 12 she 'was really well and truly an outcast'.

Something terrible happened to Beckett when she was 6 years old of which she has no memory. At this point, 'I stopped sleeping, I stopped eating, I was rake thin. . .um. . .I cut all my hair off, like I didn't want to have long hair. I didn't want to be pretty, I didn't want to be girly. . .'. From then on, self-destruction was part of Beckett's life. Beckett explains, 'it was just using my body as this chamber for all of this destructive stuff, and it was all inwards'. And so from such a young age, tried to 'gouge my eye out' with an arrow because of a nightmare in which she had 'maggots growing out of my eyes'. She would 'cut bits off [her] fingers', scratch her eyes and arms, 'burn [herself] with cigarette lighters' and chew her nails 'down to the point where the cuticle was gone'.

Beckett attempted suicide for the first time at the age of 7, which she describes her follows:

> I had a piece of rope in my room, it was from a hoodie, and. . .for some reason I'd been reading [about] sailor knots at. . .school. . .and I tied a noose and I slung it over my bunk bed and jumped off within a minute. And my sister walked in and my feet were just touching the ground. Like feet touching the ground and I was leaning forward, and she was like what are you doing? And I said, I wanna see how it feels like to die. . . .

At the age of 10, Beckett tried to cut her throat, and still has 'a scar. . .it's not a neck fold it's an actual jiggered scar, couldn't do it, hurt too much'. At the age of 11, Beckett started smoking and drinking 'not because I thought it made me feel cool, but it was like the self-destructive went away. . .and that was really weird'.

Alongside a certain level of gender fluidity, as a teenager, Beckett was certain of two things: ‘I was determined that I was straight, and that I was gonna die when I was 21.... I honestly thought that if I hadn’t committed suicide, I probably would have died, that was my deadline, the age of 21, and I had that from the age of 6’. At the age of 12, Beckett decided that she ‘needed to experiment with myself and find out what’s wrong with me’. While self-destruction started much earlier, it was then she started to cut herself, ‘but not deeply...I tried to figure out how to make myself fit. It was more of a...you know...that repressed anger and frustration went from being inwards to being outwards’. It was a period during which she felt attracted to other girls, but did not think of it as queer. At the beginning of high school, Beckett was humiliated. She recalls a particular incident as follows:

> One of the girls turned around and she said, Beckett, are you gay? And I was like, what? And she was like, are you a lesbian, are you a dyke? And I’m like, what do you mean? Well you got short hair and you really like sport and you keep staring at me when I get changed. And I’m like, I’m not staring at you, like honestly not. I’m literally, what the fuck? And it really upset me, and she’s like I think you’re gay like you’re a total dyke, like you know really – and it’s in front of my entire class. And... every time after then when I’d get changed for sport, I would turn my back and I’d face a corner, [be]cause I was like I’m not gonna give you another opportunity to do this to me.

Around the same time, Beckett met her ‘first and only boyfriend’ through a group of friends who were into reading books and loved talking about music. Cutting was replaced by reading and writing. Eventually Beckett would find herself attracted to female friends, but remained very uncertain as to whether she was straight or gay. This uncertainty was about boundaries, because she described herself as being ‘either black or white’ and not knowing ‘what grey is’. Beckett came out publicly at the age of 22 even though ‘my parents knew I was gay from the age of 10...[but] didn’t foist anything on me’. By then, Beckett was studying at a university and began forming more lasting relationships with other young women.

Something changed in the interview, roughly around the two-hour mark. Beckett was in the middle of describing how her parents came to visit her in Adelaide for her twenty-first birthday, and with her friend (who later became her partner), they all went to a beach to celebrate. She describes this occasion as follows:

> I looked at my parents and pulled out a cigarette and lit it up, first time I lit up a cigarette in front of my parents...and they looked at me and smiled. And I went, remember this time when I was doing this in the house...like [the] drug addiction things, they’re like, yeah you were tripping, and I said, you knew, they said, yeah we knew that you tried to kill yourself multiple times. I said do you remember that time I told you...that I had a really rough night about six months ago.... I’d taken a lot of drugs, and...went and stood on the tram tracks to Glenelg...and a friend followed me and pulled me off as I was watching the tram come...actually no wait I was sitting down, I wasn’t standing, I was actually sitting down so the tram would hit me at the head height.... I said [to the parents] I don’t want to be angry anymore.... I don’t want to be drug addicted and confused...I wanna know what I am, I wanna know what I like and what I love, and I want to be proud of it. I don’t want to be scared and I don’t want to be terrified of love, and I don’t want to...feel...like...there’s something wrong with me.... And my mum and dad said, okay what do you want us to do? I said...tell me honestly...if there was ever a point, were you not proud that I was your daughter, and they said no. I said, and tell me, was there any point that you thought that what

> I was doing [was] immoral or fucked up or something that I. . .um. . .something that was wrong of me to do, and they said no. . .and I said, is it okay if every couple of years every family occasion we have, I will ask you, I will tell you a secret from that past that you already probably know, and they said, yes. . .and so. . .on that beach for my 21st birthday, I died. . . . I let go of it, I didn't cry. I didn't shake, I just felt lighter.

I cannot quite pin down the moment it happened, but in the middle of the excerpt above I suddenly *saw* Beckett. This is a very strange moment to describe, given that we sat opposite each other and neither had a problem with eye contact. I was completely zoned in and suddenly I felt my perception shift. It is as if time slowed down, and in so doing, the intelligibility of Beckett's *being stood out* against the background of the room we were in. All I can say is that she looked utterly alive.

While I did not mention my shift in perception to Beckett, towards the end of the interview, she concluded that:

> My discovery as a young gay woman, young gay cis-gender woman, saved my life from a whole bunch of confusion. . . . I did die when I was 21. But this saved me because it gave me. . .something I could use. It's not a box, it's not a title, it's not gay people are us, it's you are you.

For Beckett, being 'you are you' was 'all about desire', and about wanting something badly to the point of not letting go even though she had to let go of fear, anger, confusion, frustration and self-doubt. In this sense, desire was about life and persisting to live as much as it was about sexual identity and 'the fact that I nailed [it] down, yeah, I'm gay, that's all I need to do'. Perhaps, then, this is the intensity of being I witnessed.

Few days later, I digitally recorded two separate entries in my reflective diary. These are as follows:

> It's Saturday, day after. . .my interview with Beckett. I had awful dreams last night, I didn't record an entry yesterday. . .because I was speechless. . . . Beckett was amazing. . .over two hours, with most of her talking. . . . Um. . . an incredible encounter, in terms of me listening to the narrative. . .I just wonder whether it's connected to learning how to recognise better, so it's not just listening, but it's also about recognition. I think the interview space gave her. . .lots of freedom and agency to narrate her story. . . . She tried to hang herself when she was seven. . .I didn't know what to say to this, other than just to keep company with it. . . . I'm feeling like this because I've had two interviews this week and. . .um. . .yeah and marking and everything else, I think my brain's just. . .freaking out.
>
> What strikes me about Beckett is that even though she had so much self-destruction in her life, drugs, lots of cutting. . .she had/has this amazing tenacity to live. . .has never given up on that. . .that's not to say she was seeking attention by manipulating people's attention. I think it was about working through what she was feeling, and the cuts and the body stuff was a language. . .it's really interesting how she said she died at the age of 21, which. . .she describes as a symbolical way of letting go, letting go of all the crap that she's lived with, and all the bullying. . .and identity struggles and confusion. This shows her strength and courage and, like all of them really, not one of them lacks courage (other participants). I didn't expect them not to have courage, but it's really amazing how that's coming through, or maybe that's just my response. But even if that is my response to them, I still wonder if there can be such a thing as queer courage.

The journal entries speak to the importance of listening, of paying attention, but also of being overwhelmed and exhausted. Indeed, as Boden (2018, p. 51) notes, understanding what is difficult is not difficult because of what is said in the interview, but 'because the visceral power of understanding can feel too much'. In feeling like it was all too much, I recognised the importance of recognising the intelligibility of Beckett for what it was, the symbolical death or letting go and the persistence to keep living.

Ontology and Ethics in Research Practice

Finlay (2002), p. 227) makes an interesting observation when she states that 'the researcher's task is not simply to listen to another's story: they also need to be open to being with the participant in a relationship'. This, as Boden (2018) responds, is important for suicide research because researchers are likely to hear deeply emotional, stigmatised and violent experiences and therefore need to learn how to understand them. Understanding is a relational process in so far as it emerges through dialogue between the researcher and participant. Drawing on Buber (1970), Boden (2018, p. 56) argues that to 'understand suicidality, the other must be understood holistically and met in his or her experience as it is, rather than atomised into risk factors and behaviours'. Therefore, my moment of recognition, I am arguing, related to recognising Beckett holistically: 'a deep feeling of recognition that may be characterized by the kind of ontological weight that connects us to the place where we feel both deeply ourselves and deeply connected to our common humanity' (Todres & Galvin, 2008, p. 569).

What can we make of this ontological weight Todres and Galvin are referring to? And how does it relate to research ethics? In response, my argument is that the ontological weight is a reminder that researchers are not ontologically distinct from what and who they research. By ontology, I am not referring to fundamental structures of being that are distinct from any other context, be it social, cultural or political, because terms such as being or its fundamental structures do not make sense outside the contexts through which they are interpreted (Butler, 2009). Instead, I am referring to an ontology through which *being* human can occur in relation to others, because the moment we are born, we are exposed to social and cultural assumptions and values which shape or help develop us into human beings. Thus, for instance, who I am as a distinct person is not because I happen to be, but because I developed my sense of being and identity through a process of identifying and not identifying with other human beings. Therefore, as researchers, who and what we are does not entirely depend on us, but rather emerges through the interactions with what and who we research. Furthermore, we are not entirely distinct from what and who we research, and this lack of distinction will vary and depend on many different factors. While it takes more than one interview or one project to become a researcher, on occasion our encounters offer us ethical moments through which we can reflect on the relationship between ontology and research ethics and how such ethics must include, but do not end with following a pragmatic code of ethics.

The importance of recognition is what made me, as a researcher, realise that there is more to research ethics than gaining ethical clearance. Recognition, as Butler (2004) and Lingis (1994) posit, is not a simple act of recognising oneself in the self of another, as if recognition were a cognitive event of matching up similarities between two people. Instead, recognition is when two people understand themselves to be reflected in one another, motivated by a desire to share mutual recognition (Butler, 2004, 2005; Frosh & Baraister, 2003). This kind of recognising is apparent in the account I have offered about interviewing Beckett as a suicidal other. While this claim cannot be made with certainty, it is still possible to suggest that Beckett offered me an account of what it meant for her to be young, queer and suicidal, because she could see that I recognised what she had to offer as worth knowing, honouring and respecting. This was not simple because of the aims of the pilot study, or the time given to interview Beckett. Rather, recognition was about my genuine desire to understand Beckett in her terms, without judgement and without pulling away from the difficult parts of her narrative. In this sense, establishing rapport at the beginning of the interview was just a beginning. If Beckett did not recognise something about my openness and respect towards her, I am assuming, she would not have revealed as much of herself as she did.

What, then, do we make of ethics? I want to respond to this question by considering the work of Levinas (1969, 1981) who argues that ethics comes from the encounter, and proximity to ‘the Other’, by which he means two things. First, the capitalised ‘Other’ refers to other human beings, and second, the lower-case ‘other’ refers to what lies beyond our existence as human beings, which he refers to as ‘essence’ (Levinas, 1969). Levinas (1981) considers the world human beings know as ‘the said’, because everything about the world is known through what is said about it, be it spoken, written, visual or acoustic. This knowledge can be conceptualised into themes and patterns and belongs to the Other, or human beings. The realm of ‘the other’, the theological realm on which I will not focus here, belongs to ‘the saying’, because ‘we are aware of it only what it says to us rather than through our thematization’ (Nuyen, 2000, p. 124). For Levinas, the being of the ‘I’ comes into being through encounters with Others. To put it simply for the context of this chapter, to have a sense of an ‘I’ in an existential sense, as described earlier, we are dependent on relationships with Others, who, by virtue of their existence, impinge their ‘I’s’ on our ‘I’. This is quite challenging because it means that our sense of being or having an identity is vulnerable and always tied to other human beings without our saying so. As Levinas (1981) contends, we have to reach out to other human beings in ways that will not destroy their differences while we make sense of who we are. While we may choose what human beings we relate to, the fact that we have to relate to make sense of ourselves is out of our hands, so to speak. Thus, we not only exist in fellowship with other human beings but also for them. For Levinas (1981), this is what it means to live ethically, which is about responsibility towards others.

My point about ethics, as belaboured as it might seem, is that research ethics are about responsibility, but this responsibility is not only pragmatic in so far as protecting the rights of participants is concerned. That is, responsibility in research is not only about making the conscious choice to be responsible or being responsible only for what we have done as a result of the decision-making. Rather, responsibility is also about ‘making use of an unwilled susceptibility as a resource for becoming responsive to the Other’ (Butler, 2005, p. 91). My unwilled susceptibility, or receptiveness and openness to Beckett was a sign of vulnerability not in terms of weakness, but in terms of being affected by her account in ways neither of us predicted, and to some extent, had control over. If I was emotionally moved and traumatised by the intensity of what and who I witnessed in the interview, it is because I, as a researcher, was implicated in the process of interviewing and became responsive to the suicidal Other. This responsiveness meant that I would bear witness to Beckett no matter how hard it became, for pulling back would have been, at least for me, unethical. When someone has suffered greatly, the least we can do as researchers is to be ethically responsive to their pain.

If research ethics is about responsiveness and responsibility beyond an institutional code of ethics, and if this ethics is about how researchers become who and what they are because of the company of those we research, then ethics, I am proposing, are about the arts of practice in research. In *Volumes 2* and *3* of *History of Sexuality*, Foucault (1985, 1986) argues that ethics, among other things, are about how we do what we do to, and for ourselves to know who and what we are. Techne, or arts of practice, plays a central role in this process of cultivation. As Foucault (1985, p. 10) outlines, techne is ‘those intentional and voluntary actions by which men [sic] not only set themselves rules of conduct, but also seek to transform themselves, to change themselves in their singular being…’. In this sense, techne is not simply about the relationship between oneself and activity. Instead, as Foucault (1986, p. 51) argues at length, techne is a laborious practice which takes time and creates ‘the possibility of forming oneself as a subject in control of his [sic] conduct’ (Foucault, 1985, p. 138). If we consider Foucault’s point in the context of research ethics, it is plausible to suggest that what is ethical about research ethics is not simply the following of a set of rules or prescriptions regarding research methods. Being ethical in suicide research means cultivating yourself as a researcher, knowing that this training, development and growth as a researcher will involve and evolve the company of others, some of which may test your limits. What such a testing entails will depend on individual suicide researchers and/or the projects they are working on. Regardless of the challenges, whatever we might do as suicide researchers to minimise risk, vulnerability of some kind will always be part of research ethics and this is something we need to keep company with.

Conclusion

By way of conclusion, this chapter examined the importance of going beyond the practical concerns of university human research ethics committees to understand the effects research ethics may have on the researched and the researchers in research on sensitive topics such as suicide. In so doing, the chapter drew on my experiences of unstructured qualitative interviewing queer young people about their familiarity with suicide. By drawing on philosophers and theorists such as Butler, Levinas and Foucault, I demonstrated that research ethics in the context of the pilot study I conducted are about ontology as much as they are about practical issues, because the doing and being of research ethics must always occur in relation to others, through which researchers are affected by those we listen to. Therefore, researchers, as much as the researched, are implicated in the relationship between research ethics and ontology. If research participants are open to us as researchers, then we, I am suggesting, owe it to them to be receptive and vulnerable in the process of being responsive, or ethically responsible. This means that to some extent, something about the research process is more than likely to be outside of our control as researchers.

What is to be gained from everything this chapter has debated and discussed? It is tempting to suggest that the interview had some therapeutic effects for Beckett, be it in the form of psychological relief, closure and empowerment. After all, the interview finished with me saying, ‘It’s your narrative now’, to which Beckett responded happily, ‘It is my narrative’. For me, this act of claiming her narrative was about hope. This hope did not arise from a feeling of expectation and a desire for a particular thing to happen during the interview, but rather from a feeling of trust Beckett exercised towards me in narrating what had happened to her in such detail. Hope also became evident through Beckett’s process of becoming, which she describes as: ‘I’ve stripped back what society has done to me, what my upbringing has done to me, my friends and what people at school did to me, what my exes did to me, what drugs did to me’. This process of development was important because ‘I’ve stripped it all back and I do myself’.

Thus, it is possible to speculate that hope is about a kind of stitching or suturing together through which a life worth living becomes possible, as it did, at least, for Beckett. Donald Winnicott (1975, 1983, 2006) suggests that therapy offers a renewed experience through which trauma and/or failure can be re-experienced in a different way. This is because there is an unconscious assumption that, to put it simply, there will be an opportunity to become unstuck. This does not mean that failure is renounced, but rather is brought back to the present in a way that can allow a person to move on (Chesheir & Schulz, 1989; Groarke, 2010; Mitchell, 1993). Thus, as I understand it, hope emerges as a promise of repair and renewal: if we can repair something, we can also go on.

I will not claim that the interview was therapeutic for Beckett, because this is not my claim to make. Nor will I claim that what Beckett revealed about the degree of self-destruction in her life is akin to what Winnicott (1975, 1983) had in mind when he described antisocial behaviour as a sign of hope. Instead, drawing on Winnicott's idea of hope as an explanatory tool, I want to end this chapter by suggesting that the interview revealed hope in so far as something was broken in Beckett's queer life and then, over time, was stitched together again to offer a promise of a queer life worth living. This does not mean that all queer lives must emerge from a negative space of self-destruction and struggle. Instead, it means that life can be found in the middle of struggling to live. In Beckett's words: 'the biggest advice that I can give anyone who is young and gay, and has found [their] beautiful identity. . .just because you're young and gay and you no longer want to kill yourself [be]cause you're happy with who you are, it doesn't mean that all the other shit just goes away'. The struggle may not disappear, but neither will a desire to live, and a sense of a future.

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Chapter 6
Evidence Versus Ethics: What Comes First in Psychological Practice?

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Introduction and Context

Norwegian clinical psychologists are subject to the principle declaration of evidence-based clinical practice (Norsk Psykologforening, 2007, translated and adapted from APA's policy statement from 2006). This implies that all work done by a clinical psychologist in Norway should be evidence-based. The declaration states that the principle is three-partite, consisting of (1) best available research evidence, (2) clinical expertise and (3) patient characteristics and preferences (Norsk psykologforening, 2007). The act of evidence basing is meant to keep practices research informed, which is imperative to all professionals in knowledge-based occupations.

The principle of evidence-based psychological practices is also emphasised by the Norwegian health authorities (e.g. The Norwegian Health Directorate [Helsedirektoratet], 2015), and there is a pronounced expectation that psychologists should base their clinical work on 'evidence'. The Norwegian Health Directorate also specifies that psychologists should be mindful of the costs versus the benefits of their practice and that therapy processes should be ended if the expected outcome of the therapy process does not commensurate with the use of resources (Helsedirektoratet, 2008).

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Norwegian professor of psychology Tor-Johan Ekeland (2011, p. 9) describes a politisation of mental healthcare during the course of the twentieth century, where mental health was perceived a public concern. Consequently, mental health services to a larger degree became subject to cost/benefit considerations and public mental healthcare institutions are evaluated according to their ability to reach the quantified goals set for them (Helsedirektoratet, 2020).

Shortcomings of Evidence-Based Psychological Practices

Berg (2019a, 2020, pp. 149–150) criticises evidence-based psychological practices, as described in the principle declaration, for claiming to be three-partite. Berg argues that the principle declaration is conceptually inconsistent and self-contradictory, failing to distinguish between the (legitimate and important) research on general characteristics of clinical experts and patients and individual clinical experts and patients. Thus, evidence-based psychological practices end up consisting of only the first part of the three-partite definition (best available research evidence), since the two latter parts are entirely legitimised through the former (2019a, 2020, pp. 134–135). Furthermore, Berg (2019b) puts forward that evidence-based psychological practices are supposed to work as a regulator in clinical psychology are unsuitable as ethical regulation of clinical psychological practices. He argues that the utilitarian cost/benefit approach that evidence-based practices are structured into does not allow for the complex ethical reflections he deems essential for identifying the right course of action in therapy (2019b).

Norwegian philosopher Trond Skaftnesmo (2013, p. 186) argues that scientific evidence meant to inform professional practicioners paradoxically ends up as anti-science. He claims that the aim of evidence-based practices is not to deepen insights, but rather to create an authority, which professionals must accept. Furthermore, he claims that postulations about the methodological superiority of randomised controlled trials are epistemologically unfounded (Skaftnesmo, 2013, p. 32).

According to Ekeland (2011, p. 29), research on clinical psychology is mainly, and disproportionately, concerned with treatment methods. He states that clinical practice is too complex and ambiguous for instrumentalist approaches to adequately inform the practices. In his view, clinical psychology is a highly complex field challenging the psychologists' interpretative skills and judgement building on non-instrumentalist knowledge relating to ethics, communication and comprehension of context. He therefore calls for more research on actual psychological *practices*, including for instance psychologists' views on knowledge (their epistemology) (Ekeland, 2011, p. 29).

Clinical Psychology and Ethics

Several psychologists, philosophers and thinkers (e.g. Berg, 2020; Tjeltveit, 2004) have called attention to the entanglement of psychological practice and ethics as well as scientific knowledge. Both Berg and Tjeltveit argue that psychotherapists are ethicists, as the goal of psychological therapy is to live better lives – implying the ethical question of what constitutes a good life (Wyller, 1996, p. 8). According to Tjeltveit (2004), answers to morally charged questions such as what is good and bad, right and wrong, *will* emerge from the therapeutic relationship, implicitly or explicitly. These emerging questions and answers constitute the foundation for an ethical context of psychotherapy, where therapists can practice 'at the highest possible ethical level' (Tjeltveit, 2004, p. 164). On the other hand, if the psychologist does not reflect upon the ethical context of therapy and the therapeutic relationship, the ethical context can prove ineffective, or even worse destructive (Tjeltveit, 2004).

Ethics in psychology has predominantly been subject to two guidelines: the first being the research ethics and the second the ethical guidelines that health professionals must follow (e.g. confidentiality). While these two guidelines are both correct and highly important for psychology as a field of research and as clinical practice, they only represent a limited part of ethics in psychology failing to include clinical practice as ethical in its nature.

Proximity Ethics

Gantt (2000) argues that medicalisation has rendered modern psychotherapy less able to 'genuinely understand the ethical significance of human suffering' (p. 12). Furthermore, he conceptualises Emmanuel Levinas' perspective of *the other* and holds that the critical moments—'the real work' (p. 20)—of psychotherapy happen when psychologists comply with their ethical obligation, i.e. suffering *with* the other person in the here-and-now (2000). Telleus et al. (2019) describe *proximity ethics* (*danish: nærhedsetik*) as the ethics that unfold in the psychological, existential encounter between two or more people. In this encounter, basic human phenomena such as compassion and trust are expressed, and we as humans are enabled to be empathetic and caring. Within the framework of *proximity ethics,* one can focus on conversation, vulnerabilities, belonging and closeness (danish: 'nærhed') (Telleus et al., 2019, pp. 101–102), which depends on empathy. The findings of Elliott et al. (2011) support the notion that empathy is an important concept in psychotherapy. Carl Rogers, credited for the proposition of empathy as a critical condition for change in psychotherapy, states the following: '*To sense the client's private world as if it were your own, but without ever losing the "as if" quality—this is empathy, and this seems essential to therapy*' (1957, p. 99).

Research Questions and Assumptions

Norwegian psychologists are expected to follow the principle of evidence-based psychological practices. While there is general agreement that high-quality research is crucial for the development of clinical psychology, one may argue that relying on research and evidence alone will not enable therapists to make good decisions when meeting individual patients. Based on the abovementioned assumptions that the principle of evidence-based psychological practices is insufficient as practice regulator, a need for alternative regulatory practices arises. The overarching goal of this study is thus to investigate psychologists' reflections on ethics-based psychological practices.

Methods

Design

Data collection was done through an anonymous internet-based questionnaire, using *Nettskjema*, a survey tool developed by the University of Oslo, which has a high degree of security and privacy. The questionnaire consisted of a single open-ended question, for clinical psychologists to answer about their thoughts in the beginning of a therapy process.

Data Collection

Survey

The survey was done online. It contained only one question: *What are your first thoughts when meeting a new patient, after they have presented their problem/reason for coming to you?* The question is open-ended and there was no limit regarding the length of the answers. No personal information about the respondents was collected.

Sample

The respondents were recruited from a Facebook group for Norwegian clinical psychologists. The survey was posted in the group and psychologists could volunteer to participate online. Fifty-one clinical psychologists chose to answer the survey, and all of the 51 responses are included in the analyses.

Data Analysis

The answers received were in the form of full-written sentences and reasonings. Thematic analysis was chosen as a flexible method suitable for this study (Braun & Clarke, 2006). An adapted version of the criteria from Braun and Clarke (2006) were followed: Familiarisation with the data, by reading through the material repeatedly and note initial thoughts; coding the entire data material line-by-line; categorise themes based on the codes; in the final step themes were named and checked against the material.

Findings

The conduction of thematic analysis produced three main themes: ‘the encounter’, ‘limitations’ and ‘knowledge base’. ‘The encounter’ is a theme covering the reflections on the psychologists’ role and contributions. It also refers to the psychologists’ desire to know more about the patient after the initial meeting or conversation, and a wish to get a deeper understanding of the patient’s problems. Here we find empathy, which contains the numerous reflections on feeling close to and having compassion with the patient. The theme ‘limitations’ contains reflections about whether or not they would be able to help this particular patient given inevitable limitations (e.g. economic or therapeutic). The last theme ‘knowledge base’ refers to the therapists considering what kind of research or scientific knowledge that will apply in the respective cases.

The Encounter

The Norwegian term ‘møte’ (meeting; encounter) may partly refer to the formal appointment and physically meeting the patient. More importantly, the concept has definite existential overtones, when referring to the psychological encounter that may or may not happen in a therapeutic relationship. One informant puts it this way: *‘I am mostly concerned with having an encounter with the other person, that is, to be mindful of whether there was a moment where we “met”, and what the quality of that moment was*’ (#30). It is evident that #30 is referring to (sometimes brief or rare) moments of interpersonal connection or understanding that is encounter (møte) and not only the formal, physical meeting (also møte) that is obviously happening every time a patient and psychologist are in the same room. This theme contains the psychotherapists’ reflections on the patient’s impact or impression on them, thoughts of how the therapists themselves are behaving and expressing themselves, as well as considerations about their role and contributions to the encounter, including existential reflections upon the encounter between two human beings. The importance of the first encounter was underlined by for example #46, who creates space for the coming therapy by giving room for the patient: '*I try to welcome and receive the client with an open body language, and to convey to them that I can contain whatever they relay to me–and I try to just be with [...]'.* The respondent points out the role of body language and how the therapist is working to establish trust in the relationship by opening a space, where both can linger and give possibilities for the patient to convey his/her story. The respondent emphasises the therapist's responsibility in creating a safe atmosphere.

Another respondent (#51) talks about focusing more on feelings than on thoughts, as he/she takes in the patients' story, needs and wishes in order to get an overview of his/her own experiences. The therapist needs time to understand and contain, which includes organisation of his/her own feelings and experiences. This might be an indication of raising consciousness towards his/her own reactions that might hinder or support the therapeutic process. Respondent #32 goes further in his/her reflections by calling attention to the patient's communication and relationship with feelings and the therapists' reactions to it as relevant for an understanding of the patient:

> I try to notice how this person's story and the way he/she tells it affects me, so that I can get an impression of how this particular patient relates to and communicates feelings. And I try to notice what is activated in the rapport between us that could be relevant to understand the patient's problem.

Again, attention to one's own reactions to the patient's presence and presentation seems crucial at the beginning of a therapy in the first encounter. The therapists seem serious about the necessity of not letting their own reactions confuse the therapy but acknowledge these reactions as valuable clues. In continuation of these basic introspection and patient observations, cognitive curiosity is built up. Many of the responses (~40%) indicate that the respondents' initial thoughts include a desire to learn more about the patient. They seem curious about the person's story and experiences, but also eager to understand what is not being told them directly:

> Immediately, I think about how I can understand what the other person presents as their problem, if there are any underlying aspects of the problem, and I try to understand the reason why the person seeks help, other than what is verbalised. (Respondent #35.)

The respondent's curiosity is both on what is known and unknown to the patient. She/he wants to go beyond what is presented directly in order to be able to help the patient. The outset is the particular individual and his/her presentation, and individualised cognitive knowledge. In addition to this cognitive understanding the respondents report a curiosity about how they must be feeling, which is a presupposition for empathy. About a quarter of the respondents mentioned a feeling of empathy as a primary reaction to their client's explanations or statements: *'Immediately, (I get) thoughts of how it must feel to be this person, and what I myself or other people I've met would need [in the same situation]'* (Respondent #2). It seems this psychologist actively searches within him/herself by identifying with the situation and focusing on their own needs in order to get a better understanding of the other person's needs.

Only three informants use the term ‘empathy’ explicitly, but when we include statements of wanting to understand and finding similar feelings within oneself, as well as mentioning compassion, a total of 31 responses can be counted as using this concept in the broad sense. The moral charging of this concept is quite clear; one is not concerned about oneself as therapist, but rather concentrates on seeing and understanding the patient. The concept ‘empathy’ in this broad sense is thus defined as the concept that is most unambiguously linked to ethics. This is also the most prevalent concept in the data material.

Limitations

Some respondents report thinking in utilitarian terms when they meet a patient, as money, time and therapeutic skills do not come in abundance. Some therapists have to assess the patient’s need for psychological help and consider whether or not they are in the target group of the institution they work for. In specialised mental health services and hospitals, this bureaucratic approach is often necessary; part of the psychologist’s role is to decide who will benefit the most from receiving psychological therapy and prioritise some over others. In this way, the psychotherapists’ considerations might concern people other than those who are in the therapy room; other potential patients and their needs are also implicitly taken into account. For example, respondent #12 expresses these thoughts:

> I think about the expected value and outcome [of therapy for this particular person], and whether or not the person already has some kind of support service, for instance from the mental health department in the municipality.

This psychologist finds these considerations important as they will be decisive for whether the patient will be admitted or not, which is important to know for the patient as soon as possible. The utilitarian approach thus also encompasses an element of care for this particular patient, but also other people who might be in need of help.

The concept ‘helping’ is one of most frequently occurring concepts, however, used meaning different things. One aspect is the strong wish that psychologists have to help their patients: ‘I think about how I can help the person’ (#16). This might be interpreted as representing a deep existential need and moral obligation to be helpful to other people or being associated with more technical solutions as tools and instruments. Furthermore, ‘helping’ as a concept has yet another significance in the data material, where ‘help’ is referring to institutional help, and not the existential-oriented personal help: *‘I’m first and foremost [thinking] about assessing their rights; is this a person who has the right to healthcare in the specialist health care services?’* (#12). The concept itself is thus ambiguous. On the one hand, it may reflect a genuine wish from a specific therapist to help a specific patient. On the other hand, it can represent the institutional and technical duty that the public healthcare services have to help those who have a right by law to receive help (i.e. services) (duty ethics).

Knowledge Base

In line with the therapists' reflections on whether and how to help, we find some respondents explicitly mention that they think about scientific as well as experience-based knowledge when they meet a new patient. *'My thoughts search in my conserved scientific or experience-based knowledge, to find something that is relevant to what this person is telling me'* (Respondent #31). Seemingly, they simultaneously take in what the patient is telling them and try to link it to relevant research or previous experience. Four respondents explicitly mention that they consider scientific knowledge this early on in the therapy process as parts of their total reflection on how they best can help their clients. In contrast, three other respondents explicitly distance themselves from research results. Earlier experience seems to play an important when the therapists try to figure out how to help:

> I am sometimes intrigued by their story and details in it, because it touches me and/ or gives associations to former patients, and to psychological hypotheses I have–I connect things to theory that I apply in my clinical practice (#15).

This statement focuses on the therapist's feelings and associations to both former patients and his/her own theories as basis for the encounter. Triggered by feelings and associations, the therapist connects the patient's story to knowledge that might be scientifically, or experience based. Respondent #15 also talks about his/her hypotheses, which essentially are a generalisation from one or more specific experiences. Hypotheses are created as abstractions from certain contexts, but can as well be used as a synonym for 'guesses'. It looks like both these interpretations are included in the data material. While #2 seems to use hypotheses as guesses: *'Often, I quickly make hypotheses about circumstances in the patient's life, that I want to further explore'*, #45 seems to refer to a more abstract and scientific generalisation: *'I often think about what research says when I am to position the person in a landscape of general risk factors or when I assess the degree of marginalisation'*. The therapist, apparently, utilises different approaches according to their reflections. Expertise, knowledge and competency are widely recognised as the most important foundation to get official authorisation to work as a clinical psychologist in Norway. Interestingly, there seems to be some uncertainty regarding their competency among the therapists as they look at it as a process of adaptation on their part; the psychologist needs to use their acquired psychological knowledge and rework it so that it fits the specific patient they are working with. Competency (or competence) is thus regarded as something one is constantly acquiring and which consequently does not have a static content.

Discussion

During analyses, we found three overarching themes that together account for the psychologists' reported initial thoughts when meeting a new patient. In the theme 'encounter', we found the reflections on the psychologists' role and contributions. It also referred to the psychologists' curiosity about the patient after the initial meeting or conversation, and their wish to get a deeper understanding of the patient's problems. Empathy, which contains the numerous reflections on feeling close to and compassion with the patient, was the most prominent feature. The theme 'limitations' contained reflections about their ability to help given inevitable limitations as structural, institutional and personal shortcomings. The last theme 'knowledge base' referred to the basis on which the therapists formed their hypotheses regarding a specific patient. In total, the emphasis on empathy as well as connectedness and helpfulness, outweighed and preceded thoughts about research and cost-benefit. Consequently, the principle of evidence-based practice is not followed blindly. We might ask which role does 'evidence' actually have in psychological treatment? According to Berg (2019b), evidence-based psychological practices are used to separate legitimate from illegitimate practices and basing psychological practices on the results from randomised controlled trials creates an illusion of ethical neutrality. Evidence-based practices are structured to favour utilitarianism as its normative ethics. The tendency in our data material is that evidence or research results are by no means predominant initially in therapy. A vast majority of the psychologists simply do not mention thinking about research at all when meeting a patient for the first time. Despite being subject to the principle of evidence-based practice, the explicit use of scientific knowledge is not the apparent *starting point* for this sample of 51 Norwegian psychologists.

Vaskinn et al. (2010) reported that up to 90% of Norwegian psychologists use psychometric tests, instruments and inventories (for example intelligence tests such as the Wechsler scales, inventories such Beck's depression inventory or structured diagnostic interviews such as M.I.N.I) to some degree in their practice. While the statistics reported by Vaskinn et al. (2010) do not contain any information of the frequency of use, one might expect that several of the respondents in our sample more or less frequently use tests or inventories when working with their patients. However, it seems that our respondents are more concerned with meeting their patients on an existential level and one can imagine that filling out forms can disturb the possibility of having a valuable psychological encounter or disrupt the unfolding of empathy in the therapy room. Requirements from the institutions they work for (e.g. the public specialist healthcare services) might compel them to spend time on psychometric tests rather than establishing a meaningful interpersonal connection. This may create a discrepancy between the psychologists' intentions and what they end up doing. Limited resources at various healthcare institutions may lead to a utilitarian, cost/benefit approach, that the psychologists must submit to. For example they might be required to diagnose their patient after only a few meetings and this may lead to a high pressure on the density of information that should be retrieved from the patient, thus leading to an increased use of inventories. For some types of psychological problems, the use of inventories is strictly required (Helsedirektoratet, 2020). However, our material indicates that the psychologists initially have other ideals, concerns or wishes, that are more morally charged, when entering a new therapy process. Prominent concepts in the data material, such as encounter and empathy, are value-based concepts. When prioritising these, the informants also expose their values. While Berg (2019b) is concerned that evidence-based psychological practices limit the ways ethical perspectives can be applied to evaluate psychological practice, our respondents seem capable of appraising the initial therapy process outside an explicit evidence-based perspective. By means of curiosity, understanding, empathy and their own feelings, they report to interpret the information that is unfolded in the therapy room.

Looking beyond the concepts and themes derived from the data material, we can discern a tendency that goes across concepts, themes and priorities: the intention to help the other person. While helping others in need is an essential pillar for moral thought in general, the Hippocratic legacy makes helpfulness particularly imperative for healthcare personnel, including psychologists. When the psychologists have to decide which patients they are most likely to be able to help with the available resources, the moral duty to help a person in need might be set aside with bureaucratic justifications. Trying to be helpful is an ethically founded choice (submitting to moral duty), and the question of *how* to be helpful is also, at least partly, an ethical one. The alleged tripartite evidence-based psychological practices tries to address this point (how to be helpful); best available evidence, clinical expertise and the patient's individual needs are supposed to inform each other so that the 'best' course of action (i.e. the best way to help) can be determined. Berg's (2019a, 2020, pp. 134–135) point is that this model fails to regulate practices the way it is supposed to. Given this shortcoming, there should be an opening for ethical considerations to have precedence in the question on how to be helpful. It is natural to think that the clinical expert, while being informed by best available evidence, has reflections concerning 'what is right and good to do now' and that these reflections should constitute the basis of the help the patient receives. Non-judgmentalism is essentially a virtue for psychotherapists; a few of our respondents do mention this as important when they meet patients. Tjeltveit (1986), however, claims that a certain *value conversion* often happens—from the therapist, onto the patient. The query of *whose* moral is unfolded in therapy may then be deemed in favour of the therapist, which may lead us to touch a sore point: whom do the morals really benefit? Our respondents, while favouring morally charged concepts when describing their thoughts, do not explicitly reflect on the power relations intertwined with morals. Considering the apparent preponderance of morally charged concepts, recognising the implications of these seems important. That is, when ethical considerations are prevalent in therapy, it is necessary that the psychologists acknowledge that their thoughts are indeed value based.

Closeness and the Encounter

The respondents are generally attentive to the psychological encounters that may emerge between them and their patients. According to Telleus et al. (2019), this attentiveness would be a manifestation of proximity ethics (*nærhedsetik*), that is, an ethics of closeness or intimacy. Practicing *nærhedsetik* is an ethical action. It fulfils the moral duty to help fellow human beings without concern for the costs versus benefits of the time spent with the other person. This is in stark contrast to utilitarian approaches where the financial considerations, as well as generalisations from research results, may determine whether or not a person will receive help (healthcare). With *nærhetsetik*, considerations of the specific human being are superior to economic considerations. Facilitating important psychological encounters is important for the unfolding of empathy in therapy. Our respondents use their empathetic skills as a means of getting information from and understanding and connecting with their patients. One can assume that empathy is rendered more potent if it is allowed to unfold in a meaningful encounter. Carl Rogers' quote '*To sense the client's private world as if it was your own, but without ever losing the "as if" quality–this is empathy, and this seems essential to therapy*' (1957, p. 99) beautifully illustrates empathy and professes its importance, and there is reason to assume that 'sensing the client's private world' is best done in moments of psychological connectedness. An ethics-based psychological practice requires psychologists who are highly aware and knowledgeable of how ethically based reasonings and attitudes unfold in therapy. In later years, we have seen that the institutions educating psychologists in Norway have moved away from focusing on self-development (as is common for psychoanalysts) towards training students to reflect critically about for example research findings. The latter is of course important for future professionals who will have to inform themselves on the newest scientific knowledge throughout their careers. If ethics-based psychological practice is to be successful, students need to be trained in ethical reasoning as well. As mentioned initially, the associations with ethics in psychology are often limited to (1) research ethics and (2) ethical guidelines for health professionals. An increased consciousness of the extent of ethics' presence and possible significance in therapy could enhance any therapy process, but will be crucial to an ethics-based approach. This is in line with Alan Tjeltveit's (2004) view that while questions of what is right and wrong, good or bad are bound to emerge in therapy, it is up to the therapist to use this to the advantage of the therapy and the patient—regardless of therapists being able to practice 'at the highest possible ethical level' (Tjeltveit, 2004, p. 164). According to psychologist Tor Johan Ekeland (2014), it is a mistake to think that a patient can be an object comparable to a research object, when the patient always is an acting subject; therefore, the relationship between patient and therapist is the only possible basis for psychological treatment. It is hard to imagine a psychological practice where ethical considerations are not the foundation for therapeutic choices. Although informed by scientific knowledge, it is necessarily the ethical considerations of the therapist that is momentous for the course of a therapy process. Science cannot make choices for us.

Conclusions and Implications

Berg (2019a) suggests that evidence-based psychological practices fall short as a regulatory principle. The principle is insufficient to fully cover the distinct qualities of each therapy process, each encounter. Until now, the term 'evidence-based' has been used as a demarcation between legitimate and illegitimate practices. Evidence is often self-proclaimed *neutral*, but it is not; at least the application of scientific knowledge can never be completely morally neutral. Psychological practices are fundamentally ethical, but this is often obscured by an overemphasised ideal of objectivity and neutrality. Ethics-based practices will need other justifications than what randomised controlled experiments can offer. Our study indicates that 51 psychologists tend to prioritise morally charged concepts, indicating that psychological practices are already partly implicitly based on ethics. Our respondents seem oriented towards the existential dimension of therapy and to a large degree base their work with specific patients on experiences from important psychological encounters with that person as well as earlier experiences. As this aspect seems important, one must consider the implications for the more and more common use of internet-based therapy, therapy via chat, telephone or video. When this chapter is penned, autumn of 2020, a pandemic is raging, and non-physical meetings have had a spike, therapeutic meetings included. While non-physical meetings can undoubtedly be meaningful, maintaining 'closeness' requires a special sensitivity for the morally charged content that occurs in therapy. Psychologists need to acknowledge their role as ethicists, when approaching the intricate question how to obtain 'a good life' for their patients.

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Chapter 7
Meaning-Oriented Counselling and Psychotherapy as an Ethics-Based Care Practice: Logotherapy and Existential Analysis with Cancer Patients

Daniele Bruzzone

> A man without ethics is a wild beast loosed upon this world.
> *Albert Camus*

The physician and philosopher Karl Jaspers (1919, 1932) defined limit situations (*Grenzsituationen*) as circumstances that place individual existences at risk of being 'shipwrecked'. Illness is an example of a limit situation; it makes subjects suddenly feel at the mercy of fate, as the core certainties undergirding their sense of existential security begin to falter. Yet the experience of many patients shows that, precisely in such situations, the quest for meaning intensifies, helping those who suffer to be resilient and even to undergo personal growth, despite their unfavourable circumstances. This need for meaningfulness is a protection factor of incalculable value that should be fostered and guided as part of care work.[1]

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[1] The issue of sense and non-sense in wounded existences also directly concerns healthcare practitioners, given that they are continuously in contact with suffering and the questions that stem from it. For them too, searching for meaning is a primary need: it is precisely in the face of an unavoidable destiny (and the limits of one's power to change it) that the most radical questions pose themselves (Natoli, 1986). Hence, healthcare professionals' initial and continuing education should recognize, make explicit, and explore this demand for meaning, thereby helping them to cultivate a reflexive attitude and emotional competence as core components of their professional ethics (for further details cf. Bruzzone & Musi, 2007; Bruzzone, 2014, 2020; Bruzzone & Zannini, 2021).

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Stories of Illness and Meaning-Making Processes

Illness proves to us most starkly that a person is first and foremost *a body* and yet, at the same time, is never reducible to this body. Each experience of illness is accompanied by a meaning attribution process that modifies how it is perceived by the subject and how it impacts their existence as a whole. As human beings, we are all 'simultaneously material and metaphoric beings' (Charon, 2006, p. 86), hence all events at the physical level are instantly pervaded by cultural preunderstandings (Quaranta & Ricca, 2012) and bear emotional, existential and spiritual implications that cannot be overlooked when listening to a patient (Good, 1993). Each ill person's body is itself a *story*, in that it interprets what is happening to it in light of its own past history, and at the same time, it is a *project*, in that—based on what is happening to it—it embodies a peculiar way of being-in-the-world (Heidegger, 1927; Binswanger, 1965). All changes enacted or undergone at the bodily level (growth, aging, chronic illness, disability, etc.) necessarily entail a restructuring of personal identity and existential project.

Nevertheless, it is not only *events* that determine what we are but also the story that we weave from these events. Indeed, an event (*Geschehnis*) and our lived experience of it (*Erlebnis*) are inseparable from one another (Straus, 2011), given that all happenings are immediately perceived by those experiencing them as bearing a certain meaning. The occurrence of an undesired or traumatic event can cause a 'biographical disruption' (Bury, 1982), a hiatus in our life story with the power to challenge our self-perceptions and shake our most deeply held convictions. Serious illness, from this perspective, is a key event that forces patients to radically question the meaning of their very existence. The impact of experiencing illness on patients' quality of life (Glaser & Strauss, 1975) is shaped in great part by how the patients themselves subjectively perceive—but above all by how they process—the related events (Toombs, 1993).

Thus, meaning-making plays a key role in determining the effect of critical situations and stressful events on the lives of individuals, directly impacting the well-being of patients and their families. Crystal L. Park, at the University of Connecticut, proposed a theoretical model of meaning-making with two dimensions: global meaning and situational meaning (Park & Folkman, 1997; Park, 2010). Global meaning comprises three factors: beliefs and convictions; ideals and aspirations and sense of self and purpose. Each of these aspects is directly related to a person's well-being and psychophysical health. *Global meaning* in particular 'plays an essential role in how individuals deal with situations of crisis or serious illness, influencing their adjustment and, some research suggests, even their survival' (Park, 2013, p. 41). *Situational meaning*, on the other hand, is the meaning that individuals attribute to what they are experiencing at a given point of their lives: their personal way of representing and reacting to events. Such attributions of meaning are largely determined by a person's cultural background and life story, but also by the contingent resources (whether relational, affective, religious, etc.) available to them at this juncture.

A perceived discrepancy between the meaning of a particular situation (as actually experienced) and our overall framework of reference (what we believe and aim for) generates a tension, which may be resolved by means of *assimilation* (modifying the meaning of a concrete situation) or *accommodation* (changing ourselves and our framework of reference). This twofold effort to process experience demands a change of perspective and, in some cases, a significant degree of self-transformation. Experiencing serious illness, whether chronic or terminal, can turn a person's life upside down, because it represents '*an alteration of one's relationship with the world*' (Costa & Cesana, 2019, p. 89) that generates imbalances and a profound sense of psychological suffering; nevertheless, it can also be an opportunity to revisit one's *storytelling*, with a view to developing a story about oneself that encompasses the illness experience as a further stage of growth and development.

Narrative meaning-making is the process concerning 'the existential dimension underlying coping and adjustment' (Hartog et al., 2017, p. 4); its aim is to support existential change and the corresponding 'narrative reconstruction' process. An illness may said to have been dealt with from an existential point of view 'to the extent to which the life event is integrated in the life narrative, given a new meaning and becoming a part of someone's identity' (ibid., p. 8). In the face of an experience that undermines their worldview and life view, patients must rise to the challenge of *generating a new narrative*; this presupposes the adoption of a fresh outlook on events and sometimes even a demanding process of reinterpreting their life stories (e.g. Bruzzone, 2018).

Searching for Meaning and Responsibility: The Legacy of Viktor Frankl

In the field of psychology, the question of meaning has traditionally been viewed as an ambiguous and non-scientific factor because it is difficult to objectivize (Armezzani, 2002). But excluding meaning is too great a sacrifice to be made on the altar of 'scientificity'; if psychology can tell us nothing about the inner life (*psyché*) and its meaning (*logos*), it betrays its very essence and purpose. Humanistic-existential, constructivist and phenomenological approaches have contributed to rehabilitating the dimension of meaning as one of the keys to understanding experience and human behaviour.

The first-time meaning was introduced into experimental psychology as a variable was probably when Crumbaugh and Maholick (1964) published an instrument for measuring the meaningfulness of an individual's existence: the Purpose in Life (PIL) test. The authors had been students of the Austrian psychiatrist Viktor E. Frankl, the well-known concentration camp survivor, who had based his logotherapy and existential analysis on the principle of 'will to meaning' (*Wille zum Sinn*) that is the basic strive of the human spirit to find meaning and purpose in concrete day-to-day situations (Bruzzone, 2007, 2012). Frankl, who today is viewed as the forerunner of existential and positive psychology, had observed that feelings of meaninglessness cause suffering, and existential frustration can even spring up in a ‘noogenic neurosis’ (Frankl, 2010a); from this fact, he deduced the need for a form of therapy centred ‘on life’s meaning as well as man’s search for this meaning’ (ibid., p. 51).[2] His theory informed a subsequent line of empirical research on the theme of personal quest for meaning across different life contexts (Wong & Fry, 1998; Batthyany & Guttmann, 2005; Batthyany & Ruzzo-Netzer, 2014; Thir & Batthyany, 2016).

Frankl had personally experienced the *survival value* of the inclination to seek meaning as a deportee to Nazi concentration camps during World War II (Frankl, 2006)[3]; in this, he pre-empted to some extent later theories on resilience and post-traumatic growth (Calhoun & Tedeschi, 2006).

In one of his first talks after his release from the camps, in 1946, Frankl used the title *Trotzdem Ja zum Leben sagen* for the first time to express this concept; it is possible to go on loving life despite all, on condition that life holds a meaning for us that makes it worth living.[4] But the ‘meaning’ spoken of by Frankl is not so much a purely *intellectual* notion (such as a plausible explanation for what is happening to us), but rather a primarily *ethical* matter: meaning as a goal, a purpose to be fulfilled, a good reason for resisting and even for suffering. Meaning, therefore, must be identified, pursued and achieved; it presupposes that any healthy existence will be underpinned by a tension between *being* and *ought* (Frankl, 1967, pp. 67 ff.), that is: an *ethical* tension. For this reason, the dimension of *logos* (meaning), to which the human person is naturally drawn, is never purely a question of self-actualization or self-expression (ibid., p. 71) but rather a universe of trans-subjective goals and values.

Meaning, correctly understood, is unique and singular, always arising in an unrepeatable manner that is given *ad personam* and *ad situationem*, and yet at the same time it is not created or constructed by the subject. In Frankl’s view, perceiving

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[2] Logo-therapy (from *lógos*, meaning) literally means “healing through meaning” (Frankl, 2010a, p. 125).

[3] Frankl was deported with his family in 1942, initially to the “model ghetto” of Theresienstadt, in Bohemia. In October 1944, he was transferred with his first wife, Tilly, to Auschwitz-Birkenau, where he fortunately passed Dr. Mengele’s strict selection process, and after a few days way sent on to Bavaria, first to Türkheim and later to Kaufering III (a subcamp of Dachau), where he remained until the liberation of April 1945. The Viennese psychiatrist lost his father, mother, brother and first wife, as well as a large number of friends in the concentration camps. After his return to Vienna, he was appointed Head of Neurology and Psychiatry at the General Hospital, a position that he held until 1970. His first books *Ärztliche Seelsorge* and *Ein Psycholog erlebt das Konzentrationslager* were first published in 1946. The last one, which was first translated into English on the initiative of Gordon W. Allport in 1959 under the title *From Death-Camp to Existentialism*, subsequently became a bestseller under the alternative title of *Man’s Search for Meaning* (1963) with millions of copies sold. This brought Frankl international fame and he was awarded a total of 27 *honoris causa* degrees over the remainder of his lifetime. He died on 2 September 1997.

[4] This book has recently been translated into English under the title *Yes to Life: In Spite of Everything* (Frankl, 2020).

meaning is more akin to the Gestalt intuition of a form; it is similar to what Wolfgang Köhler (1925) labelled an 'Aha!' experience, whereby a subject reorganizes his or her perceptual field based on an insight, or to the ability to grasp a situation's inherent demands, which Köhler himself (1938) called 'requiredness'. Meaning, therefore, is the link between our conscience and the transcendence's *appeal*; it is the possibility, hidden in every situation, to *respond* to life and shape ourselves.

The concept of meaning-centred psychotherapy sprang from the young Dr. Frankl's dissatisfaction with developments in *depth psychology*. His 'third Viennese School of psychotherapy' (after Freudian psychoanalysis and Adlerian individual psychology) positioned itself as a *height psychology*, founded on the spiritual (or *noetic*) dimension of human nature. While the earlier approaches had characterized neurotic ways of being as limited awareness and freedom on the part of the self, logotherapy and existential analysis were informed by the anthropological assumption that 'being-myself means being-conscious and being-responsible' (Frankl, 2000, p. 115).[5] Remaining faithful to Adler's insight that it is more important to focus on the purpose of a behaviour than on its cause, Frankl sought to comprehend the deepest need underpinning human conduct, the demand for meaning. He thus supplemented the *psychodynamic* perspective with a *noodynamic* interpretive lens that recognized moral tension as a 'primordial, wholly authentic aspiration to moral value' (ibid., p. 117). This rediscovery of the spiritual nature of human beings[6] brought *ethics* into focus in the field of psychotherapy—and medical care more generally—as a typical aspect of human existence.

Indeed, our spiritual existence is intrinsically *intentional*, insofar as it is directed towards a world of objects and other subjects. It follows that 'the spiritual being actualizes himself through being-oriented (*Bei-Sein*) to someone or something, and this quality of the spiritual being represents its most peculiar potential, its specific primordial capacity' (Frankl, 1959, p. 673). This explains why Frankl insistently claimed that the core qualities of human existence are *self-detachment* and *self-transcendence*; the former consists of the ability to look at ourselves from a distance; the latter is expressed through the ability to devote to something other than ourselves: a person to love, a task to complete, a calling to follow. Being conscious of meaning thus implies being conscious of a possibility that is waiting to be fulfilled; reawakening it implies making a person *responsible*, and when persons become

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[5] The collected writings of the young Viktor Frankl, published between 1923 and 1942, were first recollected in Italian under the editorship of Prof. Eugenio Fizzotti, and only subsequently in German and other languages. In this paper, I cite from that first edition (translations to English my own).

[6] Frankl's anthropological outlook was primarily informed by Max Scheler's phenomenology, to the extent of defining his logotherapy as "the result of an application of Max Scheler's concepts to psychotherapy" (Frankl, 1988, p. 10). The relationship between phenomenology and logotherapy can't be analysed here, however (for further details see Bruzzone, 2007; about Scheler's notion of 'spirit', see Lehmann & Klempe, 2015). Frankl was also significantly influenced by the existential analysis of Martin Heidegger and Ludwig Binswanger, with whom he kept up a constant dialogue and long-term friendship (the correspondence between Frankl and Binswanger is reconstructed and commented in Bruzzone, 2007, pp. 61–94).

aware of their own responsibility this ‘somehow forces them to make their own judgments on the ground of this responsibility’ (Frankl, 2000, p. 119).

While it is up to patients to live according to this responsibility in their everyday lives, it is the therapist’s duty to present them with it and to rescue them from the fatalism that is often associated with life’s limit situations. This was why Frankl, following Rudolf Allers, liked to define psychotherapy as an ‘education in recognizing responsibility’ (ibid, p. 130). In this perspective, it can be interpreted ‘as a means for an ethical purpose’ (ibid. p. 143). The ethical purpose, in this case, is to shape one’s existence according to meaningfulness and coherence. Life, thus, is a task that we mould by our choices: ‘every decision is a self-determination and self-determination is a self-configuration’ (Frankl, 1984, p. 143).

Alfried Längle (2005) has identified a four-step method, by which each patient can be helped to assume responsibility of his or her own being and becoming, in relation to objective meaning and values:

1. To recognize the situation: Facts and constraints, as well as degrees of indetermination and chance (*self-detachment*).
2. To evaluate possibilities according to one’s hierarchy of values (*self-transcendence*).
3. To choose the best and more significant option (*freedom*).
4. To implement and fulfil the decision made (*responsibility*).

By this process involving intellect, feeling, will and action, the suffering man is allowed to take a position towards the conditions imposed.

The ethical nature of psychotherapeutic intervention raises a deontological question: is it possible for psychotherapists to address values? In engaging, as they are obliged to do, with their patients’ individual worldviews (*Weltanschauungen*), therapists are faced with a dilemma: ‘On the one hand, the need for and the presupposition of values; on the other hand, the moral impossibility of any form of imposition’ (Frankl, 2000, p. 144). The only way to resolve the issue is to recognize responsibility as a ‘formal ethical value that constitutes the indispensable condition for all other judgements’ (ibid.). The therapist’s task, therefore, is to guide patients to the threshold of making a decision and, at that juncture, to leave them in charge. Deciding *to whom* and *for what* to be responsible is the patient’s prerogative only. Yet a therapeutic process that induces patients to ask themselves this question is a *good* therapy, in that it leads them to seek *good* and saves them from the risk of losing their autonomy, which is always inherent in situations of suffering.

And so, it happens that the condition of being ill, despite interfering with patients’ most fundamental needs, paradoxically makes them conscious of a more intimate and irreducible demand: finding a purpose in life, despite everything. Frankl’s triple route represented by the *creative, experiential and attitudinal values* encompasses the various means by which life may be endowed with meaning: through creating and producing something, or through enjoying something or someone, or through transforming oneself in relation to a destiny that cannot be changed. The last-mentioned possibility offers extraordinary scope for resilience and post-traumatic growth to those who are afflicted by incurable and fatal health conditions. Indeed, the dynamics of responsibility saves them from victimhood and allows them to recover ‘authorship’ with respect to their own life story. Sometimes ill persons are not victims of their fate but of the story they have spun about it (Hillman, 1998); their existence is no longer free, but determined and entirely taken over by a dominant theme (Binswanger, 1958). Logotherapy and existential analysis set out to prevent this danger and to restore the dignity and, insofar as possible, the authenticity of the suffering man.

Experiences of Meaning-Oriented Psychotherapy with Cancer Patients

Over 40 years have passed since the setting up, in 1977, of the Department of Psychiatry and Behavioral Science at the Memorial Sloan Kettering Cancer Centre, a research institute on New York City’s Upper East Side, since 1945 to the present day a centre of excellence in the treatment and psychological support of cancer patients and their families. Its *Meaning-Centred Psychotherapy* programs, led by Dr. William Breitbart and his team, were originally inspired by the above-outlined ideas of Viktor Frankl (1988, 1997) as well as by group psychotherapy techniques implemented by the American psychiatrist Irvin Yalom (Yalom & Greaves, 1977; Yalom, 1980).

The Sloan Kettering’s existential approach to individual and group psychotherapy (Breitbart & Poppito, 2014a, b) seems to be particularly effective at fostering coping skills (Lazarus & Folkman, 1984; Park & Folkman, 1997) in patients who suffer from chronic and terminal disease. This kind of psycho-spiritual therapeutic intervention, centred on the patients’ search for meaning, has been proved to have relevant influence in oncology and palliative care (Greenstein & Breitbart, 2000; Noguchi et al., 2006; Mangione, 2013; Rosenfeld et al., 2017).

Breitbart’s key insight was that, although clinical observation had long picked up on the importance of a sense of meaningfulness throughout the entire course of an illness, most of the available scientific evidence concerned types of treatment that were more focused on symptoms reduction (especially anxiety and depression). Hence the need to empirically investigate the role of searching for meaning in the illness stories of cancer patients, as well as the psychological support strategies that might be implemented to facilitate this quest. Following in the tradition of certain pioneering studies (Zuehlke & Watkins, 1975; Lazer, 1984), Breitbart and his staff initiated an intensive therapeutic and research program, with the aim of developing a meaning-centred method targeting individuals and groups. Their studies on the effectiveness of these interventions (Breitbart et al., 2010, 2012) have been widely acknowledged internationally as having significantly contributed to the development of psycho-oncology.

Group therapy appears to be particularly appropriate for cancer patients, perhaps due to the nature of the process through which meaning is sought, which entails the exercise of doubt, Socratic dialogue and shared reflection. The intervention format is basically quite simple:

1. Presentation of the philosophical theory of existential meaning on which the therapy is based.
2. Experiential exercises and homework.
3. Group discussion with feedback from the therapist.

The patients are invited to read selected passages from *Man's Search for Meaning* (Frankl, 2006) starting from the first session. The notion of meaning invoked is similar to that outlined by Reker and Wong (1988, p. 221), namely 'the cognizance of order, coherence and purpose in one's existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfilment'.

The aims of the therapeutic work may therefore be summarized as follows:

- Exploring, based on autobiographical retrospection, the sources of meaning in one's life.
- Becoming aware of one's personal way of interpreting and facing suffering.
- Identifying meaningful existential goals and consolidating one's capacity to adopt a constructive attitude towards life, despite illness.

Individual and group meaning-centred psychotherapy is therefore a kind of existential intervention, whose aim is to reaffirm the ethical responsibility of the patients towards their personal condition; life can be lived passively, like an imposed fate, or actively assumed as a challenge to make what is still possible and—above all—an opportunity to become a better person. This (although implicit) reference to the *good* is what allows us to address it as an ethics-based care practice.

In Italy, LAEOn (Logotherapy and Existential Analysis in Oncology) groups have been introduced by Dr. Luciana Murru at the Clinical Psychology Unit of the National Cancer Institute in Milan, a treatment centre originally set up in 1928. Their aim is to help patients to manage the psychological issues stemming from their illness, and also (and especially) to foster in them the paradoxical growth process that they can attain to the extent that they effectively integrate the illness in their life stories, without writing it off as meaningless.

The program consists of a preliminary individual session and five group sessions held weekly for about 2 h. Each encounter is divided into three parts: explaining the theory underpinning Frankl's principles for seeking meaning, individual exercises, sharing and final feedback from the therapist. Between sessions, participants are invited to complete homework assignments.

These include, among others:

- reflecting on their *personal lifeline* and the sources of meaning they have experienced;
- identifying *resilience mentors* in people who are role models for them in terms of how they have handled difficult situations;
- seeking out *personal resources* (values, experiences, competences) that have remained healthy despite their disease;

- sharing *life lessons* learned from the experience of being ill;
- and imagining their *future lives* and formulating plans and goals.

These elicitation techniques, together with the well-known power of groups to unite and encourage, have been shown to reduce participants' sense of loneliness and loss of control over their lives and to foster positive aspects (self-awareness, initiative, inner strength, deeper relationships, greater appreciation of the small things in life, confidence in the future).

The literature on post-traumatic growth (Tedeschi et al., 1998; Prati & Pierantoni, 2006) suggests that experiencing illness can stimulate positive changes in patients' self-perceptions, interpersonal relationships and existential priorities. Empirical evidence shows that personal growth following cancer is experienced by 50–90% of patients (Stanton et al., 2006). A study conducted on a sample of 39 patients who took part in LAEOn groups between November 2008 and February 2010 (Murru et al., 2013) and, later, extended to 65 patients until May 2013 (Murru et al., 2014) confirmed the effectiveness of meaning-centred group therapy in enhancing participants' psychological well-being and quality of life, accompanied by a decreasing of symptoms of depression and anxiety, as measured by a battery of research tools.[7] Above all, those showing at the beginning low meaning fulfilment and high search for meaning (usually associated to distress situations) moved towards high meaning fulfilment and low search for meaning. These gains apparently were stronger after 18 months. This means that probably this kind of intervention needs a longer time to achieve deeper change. Some of them died before that date. Nevertheless, they died struggling to preserve their dignity and to find a way of leading a life worth living, despite their destiny. Which is probably the highest ethical purpose of human existence: turning evil into good, somehow, and facing the transitoriness of human condition without succumbing to nihilism and despair.

Conclusions

Illness often represents a disruption of patients' life course. The extent to which being ill can destabilize their existence depends on whether or not they are able to integrate this experience into their life stories. Indeed, illness threatens to undermine a person's sense of meaning, seriously interfering with their desires and existential projects. When cancer or terminal patients are taken into care, it is crucial to attend to their meaning-making processes and to help them deal with their suffering in such a way that their existence can continue to be meaningful for them in spite of everything.

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[7] *Purpose in Life Questionnaire* (PIL), *Seeking of Noetic Goals Test* (SONG), *Sense of Coherence Scale* (SOC), *Mental Adjustment to Cancer*—reduced version (Mini-MAC), *Hospital Anxiety and Depression Scale* (HADS), *Psychological Well-Being Scale* (PWB).

Individual and group existential psychotherapy projects conducted with cancer patients in different countries have shown that guiding patients to explore the existential dimensions of their illness and to seek purpose in their lives can enhance their psychological well-being and help them to combat existential frustration and sense of meaninglessness, while also helping to prevent the onset of anxiety or depression syndromes.

The Austrian psychiatrist Viktor Frankl was a forerunner in the field of meaning-centred therapy; he was the first to develop a theory of motivation focused on the *will to meaning* and the characteristically human capacity to find meaning in life even in apparently desperate situations. His proposal for a 'medical care of the soul' (Frankl, 2010b) is rooted in an understanding of humans as spiritual beings oriented towards the fulfilment of purposes and values. From this anthropological standpoint, it is possible to redefine the boundaries of care as *ethics-based*, in that caring for patient's demands engaging with their individual frameworks of meaning and hierarchy of values, and helping them, not only to cope with their illnesses but above all to appreciate life up to their very last breath.

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Chapter 8
On the Care of Children Entrusted in our Hands: Reflections on the Position of Knowledge in Ethics-Based Practices

Birgit Nordtug and Cathrine Grimsgaard

Andrew is 15 years old. He has a father who suffers from mental disorders and has a problem with alcohol. Andrew says he has a very hard time at home. What is most difficult is that he has realized that there is no hope. He is quite sure that in a few years he will be just like his father. He tells that his father says to him, ‘You’re just like a shadow. A dark shadow who sneaks around in the house and eats up our food. You’re nobody’. When Andrew looks in the mirror, he sees nothing.

Three years ago, Andrew participated in a conversation group for children with parents suffering from mental disorders and/or drug abuse, mostly alcoholism. Seven boys and three girls met weekly over a period of 3 months. The weekly meetings consisted of supper, conversations and psychoeducation. Andrew tells that the group leaders encouraged them to talk about their life at home, but he felt that they did not understand what he was talking about. To him, their answers were empty words.

Edwin is 8 years old. He has a father who is very good at playing football. The best thing Edwin knows is to be with him on the football field. Then they have a great time. They cry and laugh. Dad rumples Edwin’s hair. However, sometimes something happens to Edwin’s dad. His eyes get dark. His voice gets angry. He yells and slams the doors and drinks large amounts of alcohol. He is no longer the safe and funny dad that Edwin appreciates so much. When he gets that way, he cannot stay at home. He has to move to another place. Then Edwin misses him a lot. Edwin tells the group that once while his father had been living away from home for a long time, he met him accidentally at the store. He smelled bad. His clothes were soiled and

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ragged. Edwin was in the store with some friends. His father came over to them and gave them five dollars. Then he left. As he tells this story, Edwin's eyes are blank, and he keeps getting up from his chair and sitting back down.

Edwin was a participant in one of the conversation groups that the second author participated in as a researcher during a period of 2 years. One time, the group leader asked Edwin if he thought the reason his father would get angry and drink was that he had a mental disorder. Edwin replied that he did not think his father had a mental disorder. He did not know why his father was drinking. What occupied Edwin's mind was that he missed his father. He was not looking for an explanation for his drinking. Neither was he searching for general knowledge about what it is like to be a child with parents suffering from mental disorders and/or alcohol problems. He was just trying to communicate his longing for the person he loved so much.

Background

In Norway, it is estimated that there are approximately 350,000 children who have parents with mental disorders and/or alcohol problems so serious that they have difficulty taking care of their children regularly (Torvik & Rognmo, 2011). Previously, professionals mainly focused on the parents in these situations while the children received little or no support from health and social services (Almvik & Ytterhus, 2004; Mevik & Trymbo, 2002; Östman, 2008). During the last decades, there has been an increasing awareness of the negative consequences of growing up with parents suffering from long-term and severe mental disorders and/or alcohol problems (Aamodt & Aamodt, 2005; Helsedepartementet, 2003; Meld. St. nr. 25, 1996–1997; Prop. nr. 63, 1997–98). As a consequence, there is a broad consensus among politicians and professionals today that these children may benefit from talking to professionals about what is going on in their families.

Conversation groups with a psychoeducational approach are a commonplace initiative aimed at helping children develop skills to take control over their lives (Helsedirektoratet, 2010; Nasjonalt kompetansesenter for læring og mestring, 2011; Voksne for Barn, 2008; Aamodt & Aamodt, 2005). The groups are usually organized by age and led by two group leaders. The children meet weekly or biweekly for a total of 8–12 sessions. Evidence-based guides, handbooks and manuals have been prepared to assist group leaders. Emphasis is placed on providing general knowledge that can help children to understand their parents' problems and accept that these problems are not their fault. In light of the evidence-based knowledge in the guides, handbooks and manuals, it is emphasized that the parents' problems are external to their children's existence and therefore the children cannot do anything to help their parents to get healthier. The children are made aware that they are autonomous individuals who have their own rights and needs and that they have the right to feel good even if their parents are having a hard time.

In this study, two different manuals assisted the group leaders: *Mestringsgrupper/Mastery groups* (Voksne for Barn, 2008) and SMIL, which is an acronym for *Styrke* *og mestring i livet/Strength and Mastery in Life* (Nasjonalt kompetansesenter for læring og mestring, 2011). Both manuals provide a detailed description of how conversation groups for children with parents suffering from mental disorders and/or drug abuse are supposed to be conducted. This includes guidelines for the number of gatherings, their length and their content. However, the study showed widespread ambivalence among several of the group leaders about their own use of the manual. They experienced the structure of the manual as too rigid to see and hear each child properly. Still, they did use the manual. After all, the manual was evidence-based, and they felt that they should use it if the children were to receive professional help.

A parallel may be drawn to the sociologist Arlie R. Hochschild's (1983) much quoted book *The Managed Heart*, in which she argues that numerous employees in service-work experience an emotional dissonance because their smile has become part of the service sold. Thus, they must smile even when they feel like not smiling. The organizational psychologist Nina Amble (2010) has observed similar phenomena in health care and argues that this kind of emotional dissonance may be a source of burnout. She advocates for using training programs to help care workers master their emotional dissonance. We argue for another approach than Amble; in the last part, we call for a new understanding of professionalism in which the professional's authentic emotions are part of the professional role performance.[1]

Empirical Material and Question to Be Examined

The empirical basis for this chapter is the second author's narratives about different interactive situations in seven conversation groups for children with parents suffering from mental disorders and/or alcohol problems during the period 2011–2013 (Grimsgaard, 2019). The data material for the narratives consists of about 200 h of observation and dialogues with conversation group leaders and children. A total of 50 children (20 girls and 30 boys) and 15 group leaders participated in the study. The children were between 7 and 12 years old. Each group had between 4 and 12 participants. The group leaders included social workers, nurses and psychologists.

One might say that the main finding of the study is that each child's call to be faced as a unique person with their own needs, sense of life and desire to be taken seriously as a meaning-making subject was suppressed in these conversations when the theme was home life and parental problems. When it came to other topics, such as what kind of leisure activities they enjoyed, the children's own experiences were given room in the conversations. The group leaders underlined, however, that an

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[1] It is also conceivable that the manuals may prevent burnout since they invite the group leaders to take a general position in the conversations with the children, which does not presuppose emotional involvement. But we need more empirical data to conclude anything about whether the manuals contribute to or prevent burnout or do both.

essential part of their professional practice was to meet each child with openness and interest. How to explain this inconsistency?

One possible explanation might be that the children did not communicate their desire to be taken seriously as meaning-making subjects when the theme was life at home and parental problems. However, the second author observed many situations where the children tried to communicate such a desire, sometimes through various kinds of signs, as when Edwin was rising up and down from the chair when he told about the longing for his father, and sometimes in an unambiguous way. Some descriptions of serious failure to provide care were so unambiguous that there was no doubt as to what the child was talking about. Nevertheless, it was not followed up in the conversations. As Andrew summed up, ‘No matter what I said, the group leaders didn’t care’. He knew this from the answers they gave him.

In this chapter, we argue that the inconsistency between the main finding of the study and the group leaders’ understanding that the cornerstone of their professional practice was to meet each child with openness and interest, points to a displacement in the signifying practice: From facing each child as an individual person. Towards facing each child as a category of children whose parents have certain problems, and a corresponding displacement towards general, evidence-based knowledge as a basis for determining what these children need. This displacement is taken as a premise for our discussion, and we ask: how does this happen? This question is examined by discussing the position of knowledge in the group leader’s conversations with the children about their life at home and their parents’ problems.

The displacement in the meaning production from particular knowledge about each person’s sense of life to evidence-based knowledge about preventive mental health work seems to be part of a general trend today. In our modern knowledge society, which the English sociologist Anthony Giddens (1991) terms reflexive modernity, there is a high degree of optimism about the positive effects of evidence-based knowledge on preventive mental health work (Nordtug, 2012). This is reflected in the education of future psychologists, medical practitioners, social and health workers which emphasizes evidence-based knowledge as a valid source for answering the sufferer’s call for help in a professional manner.

This tendency to meet the suffering subject with general knowledge can also be observed in treatment, with various kinds of psychoeducational initiatives, in schools and kindergartens, with teaching initiatives in mental health, and on the Internet, with evidence-based instructions and advice on how to cope with mental health problems (Tjora, 2008; Madsen, 2020). The observed tendency to suppress the individual’s sense of life in conversations about mental health therefore seems relevant for in wider context than the conversation groups that we discuss in this chapter.

Focus in the Discussion and Theoretical Framework

Andrew's and Edwin's stories show that they both suffer a lot. However, their suffering seems to be linked primarily to the fact that their basic human need for care is not being met. As pointed out, even though psychoeducation is an important aim of these groups, the children seem not to be taken seriously as meaning-making subjects. Inspired by the Lithuanian-French philosopher Emmanuel Levinas' (1906–1995) thinking about the Other's face as the starting point for an ethical act, we question whose face is being faced when the group leaders face the children's sense of life? Like many ethical theorists, Levinas seeks to connect the ethical responsibility for the present other to an encounter with a 'holy' Other. However, Levinas' project is secular. From his point of view, the 'holy' Other exists only in the present other's face as a trace of the unlimited dimension of signification, which indicates that the ethical response to the other's call for responsibility is unlimited—a never-ending project.

First, we draw on Levinas' analyses in our examination of the interaction between the group leaders and the children. To use Levinas' terms, the group leaders encounter the children by facing them as an Other. But this Other is not a trace of the unlimited dimension of signification. The Other is limited and given a definitive meaning. Namely the suffering of the children's parents seen through the lens of evidence-based knowledge about mental disorders and alcohol problems.

Then we explore what kind of discourse this displacement in the meaning production takes place in. We adopt a stance inspired by French psychoanalyst Jacques Lacan's (1901–1981) typology of discourses. Our examination of the conversations shows that the facing of the children's needs, desires and sense of life is woven into a discourse that resembles what Lacan calls the University discourse. This is a discourse that is enunciated from the position of general knowledge, which is openly communicated through the reference to evidence-based research in the guides, handbooks and manuals used by the conversation groups. However, the subject in this discourse is a rational subject, not a child who does strange things to cope with 'a very hard time at home' and who calls out for basic human care and to be taken seriously as a meaning-making subject who makes sense of life in its own way. Thus, the position of general knowledge in this discourse does not seem to support the group leaders' professional ideal of facing each child with openness and interest.

In the second part, we argue for a discursive shift in these conversations away from the University discourse that underpins the psychoeducational aim of them towards a discourse which leaves room for each child to express their needs, desires and sense of life. In other words, we make a case for a discourse that has close links to what Lacan calls the Analyst's discourse. However, we give this discourse a stronger hermeneutical basis than does Lacan, drawing on Heidegger's and Gadamer's hermeneutics. We use the ideas of these thinkers in our examination of what it should mean to take children seriously as meaning-seeking and meaning-making subjects in interactions with professionals.

The ethical in this discourse is not related to rules and principles that are formulated prior to practice in the way that it is in the psychoeducational framework of the conversation groups. The ethical is related to what goes on in concrete, living moments when children and professionals talk together. What we believe is particularly at stake in this discourse is whether or not children are met as meaning-seeking and meaning-making subjects by professionals who are open to the meaning that is being formed then and there and participating in its formation. At the same time, we believe that professionals should rely on relevant knowledge, not to secure their role as professionals but to keep the frame of listening flexible so that it is possible to hear and face the uniqueness of each child. This flexibility presupposes, however, that the knowledge is embodied and subordinated to each child's unique call for basic human care and to be taken seriously as a meaning-making subject. Then knowledge can work to ensure that children are seen as unique individuals with their own needs, sense of life and desires in the conversations with the group leaders.

Whose Face Is Being Faced?

As noted, it seems that basic human care is what the children miss most in their daily life. There are different understandings of what care is. A common one is that care prioritizes the uniqueness of the other person rather than being based on general principles and guidelines. This understanding is in accordance with one of the most cited philosophers today on ethics in caring sciences, namely Emmanuel Levinas (*see* for example Nortvedt, 2003; Nordtug, 2014). In his second major work, *Otherwise Than Being, or Beyond Essence* (1997), care is related to an unlimited responsibility for the other. It is seen as a never-ending project where the subject is under the weight of the other's call for responsibility; this involves '[bearing] the wretchedness and bankruptcy of the other, and even the responsibility that the other can have for me' (Levinas, 1997, p. 117). Levinas underlines that this responsibility for the other is not an act of will by which a person decides to be a caregiver. Care is a kind of a priori condition of ethical possibility, which one finds oneself already bound up with when facing the trace of the Other in their face—a trace which affects and effects the self-prior to its capacity to know and reflect. Thus, facing the Other in their face puts one in a position of vulnerability without any security.

In the conversation groups, the situation was quite different. The children were faced through the lens of clearly defined knowledge about the Other. In light of the group leaders' professional ideals of openness and interest, one might expect that they wanted to listen to each child's experiences with their parents' problems. The study showed that on the contrary the children's experiences of their parents' problems often were overridden by general knowledge about relevant problems in this context. Thus, the group leaders could avoid becoming emotionally involved in the children's experiences by looking at them through the lens of general knowledge. The following situation illustrates this.

Doctor Else, who works in a nearby psychiatric centre, is visiting one of the groups to answer questions about the parents' problems. The questions are formulated by the group leader on behalf of the children. But before the question session begins, the children are asked to tell Else why they are participating in the group.

> The group leader says that Else does not know them from before. Therefore, she suggests that the children tell Else what problem their parents have. In that way, she can get to know them a little better. The group leader asks Mathilde to go first. Mathilde says that the problem with her father is that he smokes and sniffs a lot. Edwin, who is Mathilde's brother, looks at her and says: 'He really doesn't sniff that much, Mathilde'. 'OK', says Mathilde, 'but he drinks alcohol'. 'That's right', says the group leader (Grimsgaard, 2019, p. 143).

Some answers are correct; others are incorrect. Mathilde's answer does not fit with what is defined as a problem in this context and it is not interpreted as a sign of something other than its denotative meaning. Words have only one meaning dimension. The group leader therefore asks her brother if he thinks their father has a mental disorder. 'Edwin replies that he does not think so. He does not think his father drinks because he has a disorder. He does not know why his father sometimes starts drinking a lot' (Grimsgaard, 2019, p. 144). As noted in the introduction, for Edwin the problem is that he misses his father and the good care he sometimes gives him, not that he lacks an explanation of his father's problems.

Mari, who is the next to tell Else why she is in the group, has observed how the group leader reacted to what Mathilde and Edwin said. She therefore knows what it means to give correct information to Else. Mari says that her father drinks alcohol and that she does not think he has a mental disorder. The group leader thanks Mari. The problem of incorrect answers arises again when Axel is invited to tell Else why he is in the group. He gets up from his chair and starts walking around. The group leader says he must come back and sit down on his chair. Axel says quickly as he looks down at the floor that the reason why he is in the group is that his mother says she wants to die. The group leader does not follow up with the same question she asked Edwin, namely whether Axel thinks his mother has a mental disorder. It seems she takes that for granted (cf. Hjelmeland & Knizek, 2017).

The group leader then asks Emma to tell why she is in the group. Emma explains that her mother is in jail because she had drugs in her bag but it was not her fault. The other children have lots of questions for Emma about what it is like in jail, but the group leader says that there is no time for such questions. The group leader does not follow up with a question on why Emma should be in a group for children with parents suffering from mental disorders and/or alcohol or drug abuse. She appears to take for granted that Emma defines her mother as a person who suffers from drug abuse. The fact that Emma believes that her mother is in jail despite being innocent suggests that Emma does not categorize her in the same manner as the group leader does.

After Emma, there is one person left to tell why he is in the group. Mats says that his father suffers from a mental disorder. Then it is time for Else to answer the questions that the group leader has come up with on behalf of the children. They are mostly about mental disorders since Else works at a psychiatric centre. The fact that only Mats has mentioned mental disorders does not seem to be a reason to not also teach the other children about mental disorders.

As the example above illustrates, the children's call for being listened to as individual persons with various needs and desires is displaced to a call for defining the parents' problems through the lens of evidence-based knowledge. Likewise, the encounter with each child's present being here and now is displaced to an expected health effect in the future: 'This will be fine for me when I become an adult' (Grimsgaard, 2019, p. 208) was the message on a note from a girl to a group-leader after the last meeting in another group.

The group leaders can therefore be criticized for doing the same thing Levinas' critics accuse him of doing, namely displacing the present other's desires and needs to the subject's encounter with an Other. To cite a critic of Levinas, '[the other] remains without an identity or a passport with which to traverse... But what of her [the other's] call to the divine? About this he [Levinas] has little to say' (Irigaray, 1986, pp. 239–240). We think the same question is relevant for the encounter with the children's experiences of the life at home: What about their call for another situation at home?

In Levinas' (1997) analyses, the responsibility for the other is beyond discourse. However, we have used his ideas to make a discourse visible. In the following, we will deepen this discourse. We will do so from the stance of a theorist who has a conceptual framework similarly to Levinas; namely Jacques Lacan. Nevertheless, there are clear differences between them precisely because one operates outside the framework of discourse, and the other within (Harasym, 1998).

What Kind of Signifying Practice Is Facing Children's Needs and Desires Woven Into?

We will examine the question of what kind of signifying practice the encounter with the children in the conversations groups is woven into using Jacques Lacan's typology of discourses. Lacan (1999) distinguishes between four types of discourses: the Master's discourse, the Hysteric's discourse, the University discourse and the Analyst's discourse. Each discourse has four positions, which are illustrated in Fig. 8.1:

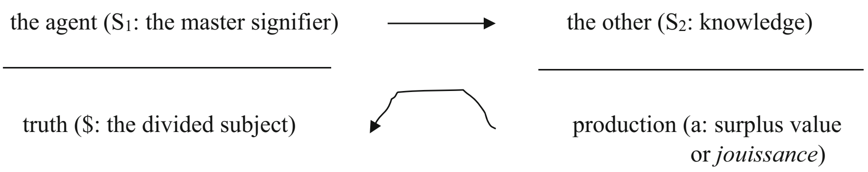

Fig. 8.1 Lacan's schema of the four positions that constitute the four discourses

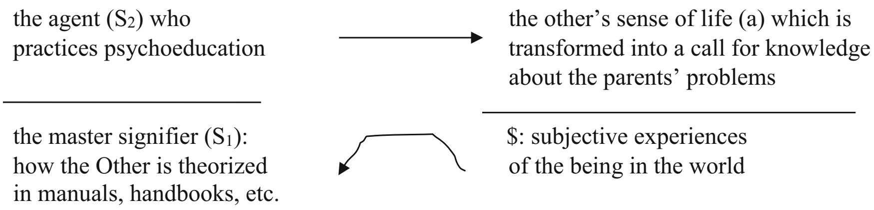

Fig. 8.2 Lacan's University discourse

The four mathemes take different positions in the schema in each of the four discourses. Whichever matheme Lacan places in one of the four positions takes on the role ascribed to that position. While we know the positions above the line, we are not conscious of what happens below the line. This means that each discourse facilitates certain things and hinders others, allowing us to see certain things while blinding us to others.

In light of the idea of unlimited semiosis, which means that a sign can never be given a definitive determination but only be represented through signs that refer to other signs (Peirce, 1974: CP: 1.339), Lacan bends the line between production and truth. Thus, the other person can never be given a definitive meaning. She or he is always in a process of becoming through the 'inner dialectic' (Østerberg, 1966, p. 10) between the consciousness and the unconsciousness; between being a particular bodily subject and being incorporated in time and history as a language subject. She or he is always something more than the said.

In terms of the Lacanian discourses, the signifying practice in the conversation groups seems to most closely resemble the University discourse, which is illustrated in Fig. 8.2 (Lacan, 1999, p. 16):

The University discourse is enunciated from the position of systematic knowledge, which is the agent of the discourse. This is openly communicated through the reference to evidence-based research in the guides, handbooks and manuals of the conversation groups, which seem to function as a source of security in the conversations with the children. The call in the other's face is seen through the lens of the parents' problems such as they are communicated by the master signifier. This means that the discourse leaves out the individual child's sense of being-in-relations and sense of being-in-the-world as such. According to Lacan, this dimension signifies and makes possible a process of *subjectivization* (to use the American Lacan-psychologist Bruce Fink's (1995) concept), in which the children's expressions of their sense of life can be experienced as their own and not as general information about what it is like to have a parent who suffers from mental disorders and/or alcohol problems.

From a Lacanian point of view, it might therefore be valid to claim that the group leaders' psychoeducational conversations with the children, based on evidence-based research in the guides, handbooks and manuals, did not leave room for the children's *subjectivity* (cf. Lacan, 2006, p. 466). As Andrew pointed out, even though the group leaders encouraged the children to talk about their sense of life, it was not possible to do it in this discourse because the feedback from the group leaders devalued what they tried to say. In this process of trying to find a mirror for his own sense of life in the words of an authority, he heard the same message he heard at home: 'You're nobody'.

In the field of therapy for eating disorders, the concept of empty words has been highlighted as a problem for many patients. The way patients talk often sounds like the therapists' textbooks (Skårderud et al., 2012). However, what these therapists do not say anything about is how their position and feedback are mirrored in their patients' words. When the girl wrote to the group leader that 'this will be fine for me when I become an adult' (Grimsgaard, 2019, p. 208), it might be an answer to the group leader's desire to be a good helper. Perhaps it is the same logic that manifests itself when patients talk as though they were the textbooks of the therapists, i.e. in response to the therapist's desire to be an expert? So how can we break out of this dynamic of confirming the professionals' desire to be a good helper or an expert in the encounter with children with parent who suffers from mental disorders and/or alcohol problems or patients suffering from eating disorders or other disorders?

Lacan identifies another possible kind of discourse that leaves room for the other's individual experiences, needs and desires. He calls this the Analyst's discourse. Like Levinas, Lacan claims that it is the professional in the position of the agent who is subjected to the other's call, not the other who should answer the professional's call or desire. He takes a different stance, however, than followers of Levinas, who argue for a knowledge-free ethical relation to the Other (*see* for example Bauman, 1993). On the contrary, Lacan claims that knowledge can function as a flexible framework that can help the professional to hear the other's call beyond the denotative dimension of language and beyond the professional's desire to be acknowledged as a good helper or as an expert. Thus, the aim of knowledge is not to secure the position of the professional as helpful or as an expert, but to keep the frame of listening flexible enough that there is room for the other's subjectivity in the conversation.

Lacan (1999, p. 16) illustrates the Analyst discourse thus (Fig. 8.3):

To be a flexible frame, knowledge has to be embodied. This means that Lacan's Analyst discourse invites the professional to work continuously with his or her knowledge, bringing it to life through an inner dialectic with the emotions awakened in the encounter with the other. The flexibility of the frame lies in this embodiment of knowledge, where knowledge is given life through emotions and experiences (Nordtug, forthcoming 2022).

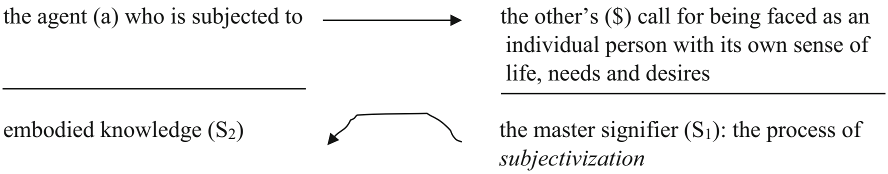

Fig. 8.3 Lacan's Analyst discourse

In keeping with Lacan's assertion that each discourse facilitates certain things and hinders others, we argue for a discursive shift in conversation groups for children with parents suffering from mental disorders and/or alcohol problems towards a discourse where each child's experience is listened to, making *subjectivization* possible. As in the Analyst's discourse, this presupposes that the group leaders are subjected to each child's *sense of life*. However, we give each child's *sense of life* a stronger interpretative dimension than does Lacan by drawing on Martin Heidegger's (1889–1976) and Hans-Georg Gadamer's (1900–2002) hermeneutics. We use ideas from their thinking in our examination of care as a matter of taking each child seriously as a meaning-making subject.

Understanding Care as Being Bound Up with the Other's Call for Meaning

According to Heidegger (2007), we are thrown into the world. Thus, we all live under conditions we neither have chosen nor can change but still have to deal with. For instance, we do not decide to be born and nor to die. Both the beginning of life and its end are beyond our control. We also have limited power over the course of life. Thus, meaning-making is an important part of being human and it helps us cope with these non-chosen conditions of life. It concerns our relationship with nature and the things around us, to other people and to ourselves. Gadamer (2010) argues that man is always seeking to understand, most often without being aware of it. We cannot be in a situation without asking ourselves what is going on. Thus, meaning-making is not seen as an act of will by which we decide to create meaning out of what we experience. It is a kind of a priori condition of being, which we find ourselves already bound up with when we are thrown into the world.

In his first major work, *Being and Time,* from 1927, Heidegger (2007) describes human existence as being-in-the-world. By using these hyphens, he highlights the inner dialectic between a person and the world. Understanding is therefore not something we acquire as independent and rational individuals, but something we *are* through our existentially engaged way of being in the world. In this way, he connects understanding to the world in which we live and act. This means that when children who have parents who suffer from mental disorders and/or alcohol problems come to conversation groups, their primary concern will not be gaining fact-based knowledge about mental disorders and drug abuse but striving to understand their own being-in-the-world together with their parents. In his previously described conversation with Doctor Else, Edwin bluntly said that he did not care why his father was drinking. What he cared about was that he missed him a lot. It was not his father's disorder but his own longing that he was trying to understand and handle. The same was probably true of Emma, whose mother was in jail. It was not her mother's substance abuse but her own emotional reactions that she was striving to understand. In several of the group gatherings, Emma communicated very ambivalent feelings towards her mother. On the one hand, she believed that she was in jail despite being innocent. On the other hand, she felt betrayed. She missed her mother and could not understand how she intentionally could do something that resulted in their no longer being together.

Another aspect of Heidegger's hermeneutics concerns the role our emotions play in how we give meaning to our being-in-the-world. As human beings, we are never neutral. We are always already engaged in the world we are trying to understand. This attunement is the primary source of our knowledge of things, ourselves and others. It is important to note that when Heidegger uses the concept attunement, he is referring to immediate moods of being-in-the-world, which are not enunciated from the position of the denotative dimension of language. At the same time, it is often from this position in language that we listen to each other—not least when our conversations are woven into the University discourse, where other dimensions of the language are left out. So, how to welcome immediate moods of being-in-the-world in conversations with children whose parents suffer from mental disorders and/or alcohol problems? Let us look at an example.

During her observations, the second author once sat on the floor together with a boy named Morten. They each had a kitten in their lap. The kittens were almost newborns, and the second author showed Morten how to hold them. He told her that he had never held a kitten before. They sat quietly together. After a while, Morten asked the second author why she had joined the group. She reminded him that she was a researcher and that she wanted to investigate what it is like for children to participate in conversation groups. Morten sat quietly for a long time. He gently stroked the kitten's back. Then he took a deep breath. He looked up at the second author and said that if she wanted to figure that out, she had to be aware that it can be very tiring for children to live with someone who is struggling with a mental disorder. Children sometimes need to get away and rest. When he had said this, he sat still and looked off into space for quite some time. Then he once again breathed deeply and began to stroke the kitten's back.

The second author was deeply moved by the incident. What Morten said had an effect on her beyond the denotative decoding of the meaning of his words. Morten's voice gave the impression of a state of exhaustion and tiredness, which made her sad. Because they sat so close to each other, it was as though Mortens's sighs moved into her body. This made her even sadder. At the same time, she was affected by the fact that he had chosen to sit so close to her and by the openness and trust he showed. His call to be taken seriously as a meaning-making subject was not something she decided to heed in light of a handbook or a guide. It was not an act of will at all. She just found herself bound up with being thrown into this situation by being present for Morten here and now. The meaningful world they shared where they influenced each other was the starting point for an effort to further understand Morten's being-in-the-world.

Whereas Heidegger primarily relates understanding to our being-in-the-world, Gadamer (2010) associates it with our openness to other people's worlds and a willingness to let one's own being-in-the-world be shaped by their being. In his major work *Truth and Method*, published in 1960, Gadamer describes the process of understanding as an act of dialogue, where the starting point is each participant's horizon of meaning. By horizon of meaning Gadamer means the totality of what we have experienced so far in life, taken for granted or considered true, both consciously and unconsciously. The aim of a hermeneutic dialogue is to bring different horizons closer together. This does not mean that everyone will reach the same understanding but rather that each participant gains a new and richer understanding of the issue from his or her point of view.

This seems to be challenging in contexts where conversations are geared towards psychoeducation and children are expected to change their horizon of meaning in line with what they are taught. However, as noted, psychoeducation does not seem to be what these children are lacking. So, this challenge seems not to be a challenge from the children's point of view. What they are lacking is much more basic. It is about the constituting of subjectivity. In light of Østerberg's (1966) mentioned concept of an 'inner dialectic', one might say that this is about reciprocity between being recognized as an individual person and recognizing others as the same; between belonging to someone who cares and can be cared for. In this inner dialectic, the subject may become 'a spark that flies between two signifiers in the process of *subjectivization*', to use Fink's (1995, p. 173) formulation. In the next section, we will elaborate on how such a dialectic can develop. We argue for daring to be authentic to each other as an alternative to being role players in a psychoeducational theatre, which the conversations between the group leaders and children seem to be when the conversations take place in the University discourse.

Subjectivization Through Belonging to Someone Who Cares and Can Be Cared for

Lacan, Heidegger, Gadamer and many other theorists agree that our subjectivity is rooted in our interdependence with other persons. The psychoanalytical tradition has especially highlighted the mother's role in the child's process of *subjectivization*, where the child experiences themselves through being touched by another and through touching another. However, this process whereby we experience ourselves as a unique person is lifelong, as is the longing to belong to someone who cares for us and for whom we can care. This longing, specifically for a caring adult, was communicated in many of the conversations the second author had with the children. When the second author asked what characterizes caring adults, the following answers came up:

> They show a sincere and honest commitment and stand with us when things are painful and difficult.
>
> They help children with different things, such as homework.
>
> They talk with the children in a way that does not make them sad.
>
> They make sure that their children have food and make sure they thrive.
>
> They take their children out. They do not leave them inside the house all the time and they make sure that they do not spend too much time alone.

The second author observed a situation where a girl was standing with a group leader working with wool. They stood next to each other and rubbed large amounts of warm soapy water into the wool. Sometimes they stopped and looked at the result. They discussed colours and shapes but did not say much more. In the background, music was playing on the radio. The mood was calm. It is easy to imagine that this situation might have been a valuable contribution to the girl's process of *subjectivization*. It is about belonging and community, being given the opportunity to experience oneself as a person who can touch others and be touched by others, and having the opportunity to step up and be welcomed as you are here and now (Engelsrud et al., 2018). That is something other than playing roles in a psychoeducational theatre. On the other hand, you never know how an informant really experiences a situation. It is something we as researchers must live with.

An Ethics-Based Practice Calls for a New Understanding of Professionalism

One consequence of establishing an ethics-based practice that is enunciated from the position of each child's call to be faced as a unique person with their own needs, sense of life and desires, and not from the position of evidence-based knowledge, is that the concept of professionalism must be redefined. We argue that this concept can no longer rely on an understanding of the professional as an expert. On the contrary, the professional is supposed to welcome the other's horizon of meaning. This presupposes, among other things, acceptance of being emotionally affected in the encounter with the other and using one's emotions as a valuable source of insight into one own's and the other's being-in-the-world. This presupposes also that the professionals can use their emotions to keep the frame of knowledge flexible. In this way, the relevance of the knowledge is continuously validated in light of the inter-bodily emotional context in each encounter. Thus, knowledge can no longer be considered a source of insight in itself as the psychoeducational framing of the conversation groups invites us to. When knowledge interacts in an inner dialectic with the emotions exchanged in the conversations, it is put on trial, losing its secure position. This also applies to evidence-based knowledge. We will elaborate on this in the following sections.

Knowledge Can No Longer Be an Aim in Itself: Challenging the Trend of Meeting the Suffering Subject with Evidence-Based Knowledge on Mental Health

As stated in the conversation group manuals, the group leaders' primary task is to help children master their difficult life situation by teaching them things that can help them to cope with daily problems at home (Voksne for Barn, 2008; Nasjonalt kompetansesenter for læring og mestring, 2011). Based on this, the group leaders taught the children how to understand their parents' problems, how to separate their own thoughts and feelings from those of their parents and how to live a more independent life.

Taking the stance of Lacan, Heidegger and Gadamer, we get a very different perspective because they emphasize how life *is* lived, not how it *should be* lived. An ethics-based practice will therefore not take form of an instructional practice where children are told what to do, but instead be an invitation for them to talk about how they cope with and find meaning in life. When a girl tells that her mother wakes her up at night to be comforted because she has been beaten by her boyfriend, and when a boy tells that his mother would exchange him for a Pokémon card if she got the chance, it reveals how these children make meaning out of their being-in-the-world. However, the second author noticed that the children's descriptions were often met with standardized statements that seemed to have little or no relevance to their being-in-the-world. The group leaders did not show the children that they were emotionally affected by what they heard nor did they take a moral stance in relation to how the children were treated by their parents. Thus, essential aspects of the children's being-in-the-world were left out of the conversations.

Emotions Can No Longer Be a Hindrance in Professional Work: Challenging the Idea of Not Being Involved

The group leaders were, however, by no means as emotionally untouched as they gave impression of being in the conversations with the children. When speaking to the second author, they told her that they were deeply touched and that they were uncertain whether what they did was right. One group leader said that she felt unsure whether she had the children's attention when she spoke to them in the superficial and simple way that the manual guided her to do. She felt that what she said had little or no relevance to the life the children lived at home. Another group leader said that what the manual told her to say would be fine if she were talking to children who lived in families whose problems were very small. However, the children in her group lived in very extreme conditions. Still, she followed the manuals. So why did she and the other group leaders suppress their emotions in their conversations with the children?

The group leaders' professional horizon of meaning seems to be based on an understanding of professionalism as formal competence and thus has clear limitations. When a central aspect of understanding, the territory of emotions, is made invisible in the conversations, the subjectivity of both the children and the professionals is violated. The children are deprived of the opportunity to experience themselves as persons who can touch others and to feel that their presence in the relationship is significant. The professionals are not given the opportunity to experience openness to the perspectives of the children, letting their horizons of meaning move them in their meaning-making. If professionals are to be able to meet children in vulnerable life situations in a way that can create room for a process of *subjectivization*, we need an understanding of professionalism that allows the professional's own emotional reactions and life experiences to be part of their horizon of meaning. This does not mean that scientific knowledge should be excluded from ethically based practices. But, as noted, this knowledge can no longer be a source of certainty in itself. It has to be subjected to the other's needs and desires and validated in an inner dialectic with the emotions awakened in the encounter with the other. Then the frame of knowledge can become flexible.

The Risk of Being Too Selfish

Arguing for the importance of using the professional's emotions as a source of insight is, however, no guarantee of an ethics-based practice. The risk is that the professional's focus on his or her own emotions and desires may become so narrow that the other's emotions, needs and desires are pushed to the background. This is what Luce Irigaray (1986) warns against in her critique of Levinas' ethics, cited above. Knowledge can offer an opportunity to open up the professional's horizon so that he or she does not become preoccupied with themselves. But, as professionals, we have to reflect upon the capabilities and limitations of the knowledge that we make use of at any given time, questioning its relevance for the other. This critical relationship to knowledge should leave its mark on the education of students in fields that work directly with suffering subjects. We would like to make some remarks on that in the final section.

Challenging the Idea That Knowledge Is External to the Person Who Uses It

The Norwegian professor of theology Svein Aage Christoffersen (2011) argues that education in professions that work with suffering subjects must focus more on developing students' practical wisdom. This wisdom can only be cultivated and developed through concrete living moments in relationships with others, he claims, and not through working with texts. Thus, Christoffersen is sceptical that books, articles and other texts can be resources in the process of cultivating and developing students' practical wisdom.

We agree with Christoffersen's call for a greater focus in education on concrete, living moments in relationships with others, but we think that practical wisdom may be more flexible if students are invited to also use relevant knowledge in these moments. Without some frame of knowledge, professionals risk viewing suffering subjects through the lens of popular psychology and common-sense knowledge of mental health, which is woven into everyday language today. But if knowledge is to function as a resource in an ethics-based practice, it must be embodied and subordinated to the suffering subject's own call.

In addition, we argue for a focus on a critical orientation to knowledge in education, where knowledge is seen as individually, relationally and contextually constituted and not as universal and given. From our point of view, an ethics-based practice presupposes that professionals can differentiate between faulty and valid knowledge and irrelevant and relevant knowledge, as well as reflect upon how a suffering subject may interpret and use the knowledge the professionals use. Thus, to participate in an ethics-based practice is also to practice knowledge responsibility.

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Chapter 9
The Construction of the Sense of Grip on Chronic Disease. Clinical and Ethical Implications from Health Psychology Perspectives

Raffaele De Luca Picione, Maria Francesca Freda, and Livia Savarese

Introduction

In the context of healthcare, the endeavor to put in dialogue an evidence-based epistemology with an ethics-based epistemology makes necessary not only to recognize some irreducible differences but also to consider the conceptual presuppositions and the frameworks of practice. Indeed, it seems that the clash between evidence and ethics is not resolvable from a mere ideological point of view and that any attempt of coordination is in reality a loss of clarity and an increase in unresolved issues.

On the one hand, the triumphal tone of the evidence-based approach in the search for efficacy tests on randomized and anonymous samples, the use of statistical risk / benefit estimates and the concept of probability to make a diagnosis and to make decisions. On the other hand, the strenuous conviction of the patient's specificity as a unique and unrepeatable, self-referential and self-determined condition. Paradoxically, we find a *trait d'union* in these two opposing visions: the lack of a processual, historical, and contextual concept through which to frame the processes of development, transformation and continuous cultural, discursive, and historical hybridization of the concept of health.

These premises lead us to support and promote the shift from a dichotomized and polarized view of health and disease towards a dialectical and bivariate view (Bertini, 2012; De Luca Picione et al., 2019b). Health and disease are not opposite

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entities or peremptory and ultimate definitions of states of fact of an immutable reality. The relationship between health and disease is not given ‘once and for all’ but it is always a function of contextual conditions, of the ability to use available resources (scientific, social, economic, cultural, etc.) and to deal with the limits imposed by difficulties and obstacles. Like any process of development, there are inevitably fluctuations, crises, and potential reorganizations (Canguilhem, 1978).

Health in this perspective becomes the “*way*” (no longer the “means,” and no longer the “*end*”) with which people face difficulties, crises, and obstacles day after day (De Luca Picione et al., 2019b).

Every vital process—in its complexity of biological, psychological, social, and cultural interconnection—is always characterized in dynamic terms, where conditions of fixity, stasis, and hypostatization represent the most striking forms of discomfort and suffering (somatic, psychic, social). The static condition in a vital process therefore represents the sclerotization of development processes and of the relational bonds between people and their contexts (Venuleo et al., 2020; Venezia et al., 2019; De Luca Picione et al., 2017, 2018).

Therefore, health and disease must be read as dynamic processes that present fluctuations and continuous reequilibration, like any other development process. In this perspective, moments of crisis and rupture can intervene in the health process which can be read as signs of the need to reorganize new forms of relationship with the context, whose prerogatives are flexibility, transformation over time, contextual plasticity, restructuring from its fractures, crises, and discontinuities.

Illness, Diagnosis, and Chronicity: Complex Aspects of Contemporary Healthcare Scenarios

Faced with the disease, people make experience of a crisis of continuity of their sensemaking systems, of their social and professional routines, a discontinuity of their relational and emotional bonds. In general, a person struggling with an illness experiences a biographical event of discontinuity of her own subjectivity (Bury, 1982; Freda et al., 2019a, b; De Luca Picione & Valsiner, 2017; Savarese et al., 2020).

One of the greatest difficulties experienced by people affected by a disease is about sensemaking process. This difficulty represents a real developmental task for the sick person (Freda et al., 2015a) and is emotionally connoted by anxiety related to death scenarios, the perception of uncertainty, and the unpredictability of one’s own life. Again, the person may feel depressed by the scenario of no longer being useful and to consider as disconnected from her identity and affective ties (Martino et al., 2016).

In such circumstances, a double function of diagnosis is frequently observed, through its process of naming the disease; on the one hand, it generates relief by enclosing within an ordered, predictable, and shareable label a set of symptoms that until then had manifested themselves in an incomprehensible and apparently chaotic manner. On the other hand, the diagnosis—within the affective-cultural coordinates of the subjects—carries out an action of reification and objectification of the disease. This entails the risk that the disease saturates the sense of experience within the system of meanings already available and given (Freda & De Luca Picione, 2017a, b; Lemmo et al., 2020).

In the contemporary scenario, it is in evidence the demand for increasing autonomy of patients and empowerment of their own care processes, the acquisition of skills to treat the evolution of their health conditions, and the search for new forms of well-being and quality of life in connection with contexts of belonging. Today more than ever, we are called to deal with the question of what it means to support development and autonomy processes when one is in chronic conditions (Graffigna et al., 2017a, b). Therefore, it is of great relevance:

- To promote processes of progressive empowerment and reconstruction of future planning when you know that you will be sick for life.
- To promote the transition from positions of dependence on one's medical conditions to more active and less delegating positions.
- To promote interventions to develop the patient's health engagement, not only in the direction of positions of compliance and adherence to medical prescriptions but of greater awareness of one's diagnosis and the characteristics of one's disease, supporting the patient's ability to activate competent ways and to connect with the services and support networks distributed throughout the territory.

Chronic disease today is an exponentially increasing phenomenon that characterizes welfare societies, largely attributable to the increase in life expectancy and the improvement of detection and early-detection techniques (Hurst et al., 2018; Dicker et al., 2018, Dicé & Zoena, 2017; Dicé et al., 2018a, b). This issue is at the center of the agenda of health and political institutions because it requires greater and wider services for the assistance of patients who need care for long years.

For this reason, given the diffusion and the need to arrive at effective and economically sustainable systems for managing these aspects, in recent decades there have been numerous models between behavioral medicine and psychology that have advanced proposals on chronicity (De Ridder et al., 2008). The main paradigms include the *chronic care model* (Coleman et al., 2009), the *self-management paradigm* (Lorig et al., 2001; Leventhal et al., 2008), *engagement* (Graffigna et al., 2017a, b), *patient empowerment* (Aujoulat et al., 2007), etc. These models represent an important turning point in the field of health towards the recognition of the centrality of the person in determining her health, in the wake of the personalization of care. The focus of most of them is on their effectiveness with respect to the achievement of specific health outcomes or healthy behaviors.

The Sense of Grip: Semiotic Development of the Ability to Treat One's Health Conditions

It is within these reflections on the issues of contemporary health debate that we have developed the semiotic-clinical construct of *"Sense of Grip on Chronic Disease,"* with which we intend to treat the relationship between the person and chronic disease starting from a semiotic conception of mind (Salvatore & Freda, 2011; De Luca Picione, 2020a, b).

Using an imagine, grip reminds us of grip of a tennis player that must be able to assume a position suited to one's physical characteristics, to grasp the variations in the trajectory of the tennis ball and environmental variations, by orienting the racket in the most suitable way to intercept it. Looking at the photos taken of the tennis players, we are struck by the anything but static pose of the athletes, looking for the right position to receive the blow. Like a tennis player, each person affected by a disease has different personality characteristics, relates to a certain environment with different constraints and opportunities, and is confronted with specific characteristics that the disease assumes.

At the heart of our conceptual proposal is the sensemaking process, understood as a continuous activity of construction, regulation, and development of personal experience within relational contexts (Freda, 2011; Valsiner, 2007; Salvatore, 2016; De Luca Picione & Freda, 2016a, b, c; Lehman et al., 2019).

In our conceptual and clinical work, the difference between *sense* and *meaning* has a great value. Starting from a long tradition in cultural psychology, semiotics, and narrative studies (Valsiner, 2007, 2014, 2021; Salvatore, 2016, 2019; Neuman, 2003, 2014; Vygotsky, 1978; Bruner, 1990; Salvatore et al., 2018, 2021a), we consider such a difference dwells on temporal, dynamic, contextual, and pragmatic aspects. Accordingly, we use "*sense*" specifically addressing a global process of construction of contextual system of relations in a temporal development. Meaning is adoperated in a more limited use, namely about a process of semantic connections able to denote specific references (Freda, 2008; De Luca Picione, 2015; De Luca Picione & Freda, 2012, 2014, 2016a). If meaning provides a static depiction, then sense constitutes a developmental trajectory of relations.

The starting point of our construct is the enhancement of the knowledge acquired through the direct experience of people affected by the disease (lay experience) and the negotiation of treatments and behavioral indications aimed at seeking a balance (a sort of *"personalized optimum"*) in the doctor–patient relationship, the vector of which becomes the promotion of processes of autonomy in care.

Therefore, the narration represents a tool to solicit and to understand the perspectives of people with chronic disease experience. Considering the narration as one of the formidable forms of sensemaking processes, we have developed an interview on SoGoD with the intention of offering a clinical tool of agile administration and analysis. That interview can allow us to highlight the main characteristics of the relationship between person and disease in reference of one's own contexts (Freda & De Luca Picione, 2017a, b). From the use of this tool in different clinical research contexts, we have identified three SoGoD profiles that show interesting procedural aspects of the way to treat, manage, and share disease conditions within one's own relational scenarios.

Our model focuses on the achievement of "*possible health,*" namely a dynamic form that is situated, contextual, and referred to the resources available for development. This implication is deeply ethical, and not in opposition to the evidence. In fact, we consider fundamental to emphasize the experience and the practices of people who deal with the disease every day, and the way in which they integrate scientific knowledge, protocol, and medical directives. The patient ceases to be the passive user of the treatment and gradually becomes an active and responsible protagonist. By the Sense of Grip model, we intend to rebalance the expertise between the doctor and the patient, recognizing at the same time both the asymmetry and complementarity of the different forms of knowledge.

In this theoretical and conceptual framework, our SoGoD construct refers to the semiotic skills that the person uses to master the relationship with the disease by unfolding various degrees of flexibility, differentiation, and adaptation to the variability of self-experience and of the contexts. The conceptual model of the SoGoD is born within an abductive research paradigm, in a recursive dialogue between the main references in the literature cited in the introductory part and the data we collected during our last 10-year research program with people affected by chronic disease both in the pediatric patient and adults (Freda et al., 2016, 2019a, b; Savarese, 2018; Savarese et al., 2018).

The words we have chosen to define this conceptual proposal aim to highlight two fundamental aspects of our model: (a) the term *"sense"* focuses on the centrality of the person's sensemaking processes in everyday life. The second term *"grip"* was chosen by us with the intention of highlighting its necessarily flexible nature, capable of following the variations both in the course of one's health needs and in the manifestations of the disease. For these reasons, it would be completely unsuccessful to propose general and standard objectives, goals, and methodologies to pursue them.

At the same time, we cannot imagine that it will be possible to develop and propose personalized and tailored protocols and methodologies for each individual. This would make our proposal illusory and not suitable for meeting the sustainability of taking care of people with chronic diseases. Our proposal aims to intervene on the analysis and promotion of the sensemaking processes themselves, rather than on the promotion of standardized protocols and preordered objectives.

This means that we intend to start from a narrative analysis of illness sensemaking processes that the person realizes when we meet her. We start from this analysis to plan and to implement intervention proposals aimed at supporting the person, with the aim of stimulating her semiotic resources in terms of autonomy and development of the most effective paths and actions to achieve her health goals.

Trying to summarize our model schematically, we could therefore say that the SoGoD is a semiotic function of the resources available at a given moment for the person in relation to her illness, healthcare relationship, and life contexts.

The Narrative Functions for the Exploration of Sense of Grip on the Disease (SoGoD)

Addressing our attention to the analysis of the narratives of people with chronic diseases means exploring the characteristics of sensemaking processes related to living with the disease. The focus is on the structural and processual characteristics of sensemaking in narrative constructions with the aim of understanding how people relate to the main issues inherent in living with chronic disease. We have selected five main narrative functions that allow us to understand the relationship between the person and chronic disease in everyday experience. For each of them, we have identified a number of *Sensemaking Modalities* (SM), which give an account of some of the main features of the sensemaking process. These SM were derived from our previous research on narratives of people with chronic disease (Freda et al., 2019a, b; Savarese et al., 2020; De Luca Picione et al., 2015, 2017; De Luca Picione, Martino & Troisi, 2019; Martino et al., 2019a, b). They correspond to as many functions that in narration are put into action to regulate the relationship between the person and chronic disease. By the terms "*sensemaking modalities*" (SM), we refer to the product of the semiotic narrative analysis which is aimed at detecting the logics and the process of the narrative construction of the links between the elements of the experience, as well as to the general purpose and objectives to which the narration, in its agentive function, responds (Peirce, 1935; Baldwin, 2009; Proulx & Inzlicht, 2012; De Luca Picione et al., 2018). Therefore, analytical attention was not only paid to the semantic contents of the narration (the "what" the narrator deals with) but also to the characteristics of the links that orient the points of connection between the elements of the experience within each domain (the "*how*" the narrator presents and articulates her story) (De Luca Picione et al., 2017).

The main narrative functions we identified that regulate the construction of the sense of the experience of chronic disease are as follows:

1. Temporal organization of the narrative.
2. Degree of integration of the disease in one's life narrative.
3. Articulation of the emotional experience.
4. Sharing of experience.
5. Agentive function.

We will provide in the following a definition of each function and the SM identified for each of them.

1. *The temporal organization of the narrative.* This function allows us to refer to the process of narrative connection of the disease experience within a spatial and temporal framework. This allows the individual to subjectively organize their experience in a narrative form and at the same time to share it with others. Aspects of temporal and autobiographical coherence have to do with this function. The narration allows to bring together, in a three-dimensional way (past-present-future), the different lines of time (De Luca Picione et al., 2015, 2017, 2018;

Brockmeier, 2000). How is the narrative articulated in relation to the disease? It tells of a before and an after? Is there a story of a transformation of experience in relation to the disease over time or does narrative time seem "stuck" at the time of diagnosis? These are the questions referring to the quality of the narrative construction process of meaning, which we try to answer in the process of semiotic analysis of narratives. We believe that three main modalities allow to synthesize some nuances of this process (Freda et al., 2019a, b; Savarese et al. 2020): A. *Absent*. There is a lack of a process of dynamic articulation of the narrative of the disease. It seems the diagnosis was not registered as a discontinuity, and the narration was not articulated in a before and after the tragic event. B. *Blocked*. Time seems trapped in the moment of receiving the diagnosis. The narrative expresses the same level of interruption of narrative continuity experienced at the moment of receipt of the diagnosis despite the past time. C. *Transformation*. The narration gives an account of the processes of articulation of a before and an after, of a series of narrative transformations of the relationship with the disease in which time is a catalyst for new meanings to arrive at and to rework.

2. *Degree of integration of the disease in one's own life narrative*. By this function, we refer to the propositional process of narration. The narrative process constitutes the individual theory of experience based on subjective norms, values, and references, without a need for verification (Thornton, 2010; Bruner, 1990). With this aspect, our aim is to analyze the process of integrating the experience of illness into one's life narrative. It is a process that has to do with the degree of integration of the experience of the illness within the narrative of the *"canon*." By the means of the confrontation with canonic/normative forms (namely organization of orienting values), the person starts a dialogical process of semiotic integration. Thus, the illness can assume several meanings: illness as essential aspect of one's own experience and identity construction, or opposite it remains a detached, isolated, alien, or "enemy" experience, or a threat for an ideal and idealized form. The following MSs identified for this domain are: A. *Conflict*. The narrative does not integrate the elements of the disease experience into a narrative of oneself that is organic and coherent from a causal and organizational point of view. Aspects of the disease appear unacceptable and always in friction with all other activities or experiences. B. *Tolerance—resignation*. The narrative assimilates, without any transformation, the disease element as a "chronicle," without mediating, negotiating the meanings based on one's experiences/specificities. The disease is recognized and named, however, exclusively as an object with which one cannot help but confront. C. *Prospective cohabitation*. The narrative articulates the element of the disease within a broad self-representation oriented towards eudaimonic well-being and not just the absence of disease/symptoms. The person not only recognizes the disease but also is capable of developing forms of experiences that are capable of integrating resources and limits related to the disease.
3. *Narrative articulation of the emotional experience.* This function refers to the narration as a dynamic multilevel system, able to regulate the relationship

between affects and signification. The interconnection between levels of affective-bodily activation and cognitive processes mediated by language establishes the necessary foundations for the processes of emotional regulation both in quantitative and qualitative terms (Gross, 2014; Barrett, 2017; Velotti et al., 2013; Valsiner, 2007; Tronick, 2009; Salvatore et al., 2021b). The physiological correlates of experience are connected to an emotional category and orient the narrative. The narration produced in turn affects the physiological correlates of the primary affective experience, generating an emotional and physiological regulation. The connection between emotion and event, mediated by the narrative device, establishes the foundations and the containment of the emotional regulation processes (Matte Blanco, 1975; Valsiner & De Luca Picione, 2017; Tronick, 2009) and meta-reflections on the new version of the experience (Esposito, Freda & De Luca Picione, 2016). With this domain, we therefore analyze the presence of processes of naming and differentiating emotions and feelings. We observe different qualities and processes of the emotional experiences, based on the degree of generalization of the emotion within the narrative, the articulation of the emotional experience that contemplates variegated and ambivalent aspects of the experience, and richness of narrative passages dedicated to the emotional experience. The following are the SM identified for this domain: A. *Vagueness* . The narrative process uses very generic terms with little emotional connotation, polarized on very generalized and basic dimensions (good/bad, good/bad, pleasant/unpleasant, inside/outside, etc.). B. *Discretization*. The ability to use a specific emotional lexicon is observed. At this next level of sophistication of the emotion/narration process, we find the use of more detailed forms of emotional naming, even if it is a mainly linear and a-contextual descriptive level. C. *Differentiation*. This process in narrative terms is shown as the ability to name in reference to specific conditions, contexts, and actors. Furthermore, at this level, the narrative is also capable of expressing the affective nuances, the ambivalences, the coexistence of opposite affective tones, and the different gradations and emotional transformations that occurred over the time of the experience.

4. *Sharing of the experience*. Through this function, we analyze the storytelling process with reference to sharing the experience of illness with other people and the meaning attributed to this exchange. This refers to the organization of connections between the self and the world, and between oneself and others. Narration works as a device for sharing with others, organizing and reorganizing relationship plans in its various aspects and roles (Rimé, 2009; Barone et al., 2019). The SM by which we differentiate the narratives belonging to this function are the following: A. *Isolation*. The person avoids talking about his illness. The disease topic or related aspects are definitely kept out. B. *Information*. The person uses the disease narrative for purely informational purposes. The form appears rather stereotyped, full of forms of common sense, and it is repeated in a repetitive and unchanged way (see the concept of dominant narrative by Gonçalves et al., 2011). In this case, the narrative seems to have just a function of informing without any availability to accept other opinions. C. *Discursive negotiation*. The

purpose of narrating one's own experience is to show one's point of view and to transform one's narrative into dialogue with the other.

5. *Agentive function.* By this function, we mean the relationship between the narrative construction of experience and the ability to make decisions and pursue actions with the aim of impacting events and modifying aspects of one's life scenarios. The narration is configured as an open and dynamic process of construction, regulation, and transformation of one's agency (De Luca Picione et al., 2018; De Luca Picione, Martino & Trois, 2019). Narrative construction is a sine qua non for the implementation of intentional behavior. This domain refers the use of the narrative to construct symbolic resources, which are functional to the adoption of a proactive, participatory, autonomous position in defining the practices and behaviors to be taken in the daily management of the disease. We then proceed to list the main SM identified for this function: A. *Limiting*. The narratives are characterized by processes of limiting or avoiding activities (mainly about social, recreational, and daily life). Avoidance is the main way for dealing with the disease in everyday life. B. *Executive*. These are narratives in which the total adherence to medical suggestions is leveraged and there is no mediation process between these and the subjective background of experiences. The agentive dimension is totally adherent (collapsed) on the prescription and implementation of protocols. C. *Flexible*. The agentive function does not present a unique way of coping with the experience of illness, rather it tells of a process of continuous negotiation between personal desires and needs and the procedures necessary for the management of the disease. We find a flexible, dynamic, and heterogeneous set of strategies, configured according to contexts, needs, and resources.

Below is the summary grid of the narrative functions and the respective sensemaking modalities (SM) (Table 8.1):

Table 8.1 The narrative functions for the sensemaking of the experience of chronic disease and the sensemaking modalities for each of them

Narrative functions	SM
Temporal organization	Absent
	Blocked
	Transformation
Integration of the disease in one's life narrative	Conflict
	Tolerance/resignation
	Prospective cohabitation
Articulation of the emotional experience	Vagueness
	Discretization
	Differentiation
Sharing of experience	Isolation
	Information
	Negotiation
Agentive function	Limiting
	Executive
	Flexible

Specific Configurations of the Sense of Grip: The Study of Three Recurring Profiles

Through several researches conducted with the use of an ad hoc narrative interview[1] to explore the Sense of Grip on Chronic Disease (Savarese et al., 2017, 2018, 2020; Freda et al., 2016, 2019a, b), we have identified some specific and recurring profiles. Through the use of statistical cluster analysis procedures carried out on the codification of the narratives according to the SM of the five narrative functions described above, it was possible to observe how three configurations are well recurrent.

The use of the multidimensional analysis (specifically multiple correspondence analysis and cluster analysis as statistical methodology) has been chosen for its value to treat qualitative data and to extrapolate recurrent configurations of variables. Multiple correspondence analysis and cluster analysis provide an interesting support in a semiotic cultural perspective of research (Salvatore et al., 2019; Salvatore, 2016; Neuman, 2014) since these statistical methods allow us to deal with qualitative data, and their purpose is not that of measuring a standardized property (i.e., level of an ability), but to extract forms of order in the row data. Within our research work, this issue has a strong implication: we firstly interpret interviews according our coding system of semiotic modalities (SM) grid, then we run a cluster analysis to find recurrent configurations of modalities within each narrative function in organizing the sense of the disease experience. The detected recurrent "profiles" are not used in order to define taxonomic instruments, rigid assessments based on evidence-based

Interview on the sense of grip on the disease	
1	When and how did you discover that you suffer from a medical condition?
2	When did you realize that you were affected by (*name of the disease*)? How did you feel?
3	In your experience, are the symptoms associated with anything in particular? (if they refer to emotions, ask: what do you mean by emotion/stress?)
4	Describe your illness in three words, explaining why you chose each of these
5	Tell me about a salient symptomatic episode/the one that was most significant and recent for you (within the last 6 months or, if there has not been one, within the last year)
6	In this situation, in your opinion, things would have gone differently if...
7	How do you talk about (*name of the disease*) with others? Which words do you use to define it? How is it for you to talk about it?
8	Is there anyone other than your family who is aware that you have this disease? How did you tell him?
9	What do you do when a symptomatic attack occurs? How do you feel?
10	What is your relationship with drugs? Are you taking prophylaxis?
11	Is there something or someone who you feel more helpful in managing the disease?
12	Do you feel that the disease interferes with your work and leisure activities?
13	Do you want to add something that we did not ask?

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[1] The semi-structured interview of the sense of grip on the disease

notions (let us think the profiles of personality in psychiatry or psychopathology). Rather, these profiles help us to consider some interconnected dynamics and variable developments of different strategies of management, thinking, evaluating, relating, and acting. They are formulated along a tension between generalization and idiography (to deepen these considerations in the cross-fields of health, clinical, and cultural psychology, *see* the VIII Volume of Yearbook of Idiographic Science—De Luca Picione et al., 2019b; but also, Solano, 2019).

The identification of these profiles has for us a primarily convertible value in clinical terms, as it allows us to highlight some transversal areas of chronicity and to grasp the differences in terms of the narrative processes of the person in relation to his illness. The Sense of Grip construct integrates a double logic:

- On the one hand, a research logic aimed at formulating knowledge capable of abstraction. That is to say, the aim is to arrive to a conceptual model, capable of reading the variability and differences of specific phenomenal occurrences. It is an abductive logic aimed at formulating general abstract models starting from specific procedural dimensions, rather than referring to strict empirical evidence (De Luca Picione et al., 2019b; Salvatore & Valsiner, 2010; De Luca Picione, 2015, 2020a, b);
- On the other hand, a logic based on the ethics of fully recognizing the subjective implications of the disease. Every psychological process is always instantiated in space-time, contextual and historical terms. The patient is always within a story that provides frames of meaning to her experience, intersubjective relationships, and emotional experiences.

The encounter of these two fronts, only apparently irreconcilable, provides an orientation trajectory of interventions in the clinical context and for the development of the healthcare relationship (Freda et al., 2015b; Dicé et al., 2018a, b; Freda & De Luca Picione, 2017a, b). We proceed below to describe the profiles through some guidelines to identify them and some proposals for differentiated intervention settings.

The first profile, called “*Dynamic*” SoGoD Profile, is mainly characterized by the frequency of semiotic modalities of sharing, coexistence, flexibility, and transformation. The narratives that fall into this profile are characterized by the presence of passages that refer to the sharing of the narration of one’s own experience of illness with people considered significant, and by the narration of an intra-inter-subjective scenario in which the illness has been integrated as one aspect of the experience. The experience is characterized by multiple aspects and the pursuit of eudaimonic well-being objectives. Furthermore, the narrative skills of the subjects who fall into this profile are functional to the implementation of flexible strategies to cope with the disease in everyday life that adapt to the variability of environmental, personal, and disease-related conditions. The strategies implemented seem to draw on the wealth of personal experience, through a negotiation between general therapeutic indications, health needs, and development projects.

The second profile, which we have called “*Adempitive*” SoGoD profile, is about a full compliance attitude. This profile is characterized by a high frequency of information modalities, tolerance/resignation, execution, and vagueness. The narratives that fall into this profile are characterized by the purely informative aspects of communication. The story of one's experience has the mere function of making the other aware of the concrete aspects relating to one's illness without the willingness to receive or seek support or sharing points of view. Illness is experienced as an aspect of one's experience with which to live in a sort of resignation. Disease management is performed on the basis of observance of the therapeutic indications received from doctors. Finally, a modality of regulation of emotions that we have defined as "vague" is significant, to refer to narratives in which the affective dimension is characterized by a generic reference to too broad and nonspecific categories of affective value, without nuances or ambivalences.

The third profile, which we have called "*Combative*" SoGoD profile, is characterized by a high frequency of limiting, conflicting modes, and the absence of temporality. This profile is mainly characterized by a limiting modality in the domain of agentive processes, with which we identify disease management processes aimed at avoiding, reducing, and even eliminating any risks connected to the triggering of symptoms or worsening of health conditions. The presence of the disease is accompanied by conflicting experiences, as if it had never been accepted, despite the time that has passed since diagnosis. In fact, time does not seem to flow, does not become a promoter of the processes of elaboration of the experience of the disease, in the narratives of these subjects who seem blocked at the time of the diagnosis.

Methodological and Clinical Implications of the Profiles of the Sense of Grip

The richness of the results of our researches has stimulated a series of clinical reflections. The identification of the three profiles seems extremely relevant to us as it can result in the activation of ad hoc lines of psychological intervention in support of the SoGoD. We highlight the main aspects on which to orient targeted interventions for each profile, proceeding to distinguish the needs of patients and the purposes to be promoted in the doctor–patient relationship.

The subjects whose narratives fall within the first "*Dynamic*" profile show considerable flexibility skills in the ability to cope with the disease. They are carriers of the need to recognize themselves fully competent in the health relationship. The objectives of the doctor–patient relationship have to do with accompanying and supporting the patient in changes related to the pathology and/or life stages, and in the possibility of being recognized as an expert patient. That in order to promote a sense of agency that also draws on the possibility of expressing oneself in supportive prosocial behaviors towards people who share the same illness experience (Esposito et al., 2017).

People whose narratives fall into the "*Adempitive*" profile are recognized as carriers of the need to be supported in the ability to use information as a resource of meaning, in the implementation of emotional skills to recognize ambivalent experiences and negative emotions associated with experience of illness. This profile appears as characterized by a general tendency to fully compliance to medical prescriptions, but a scarcely engagement in personalizing the experience. The developmental task therefore is about to subjectivize one's own relationship with the disease by developing self-management skills. The purpose of the healthcare relationship must therefore aim at recognizing the skills of patients and helping them to subjectivize the illness experience, accompanying them in the exploration of needs and motivations by providing feedback to help them in the gradual process of building autonomy.

Finally, the identification of the third "*Combative*" profile makes possible to highlight the need of patients to integrate the intrinsic constraints/limits of the illness experience, to receive information that can be accepted in the doctor–patient relationship, by pursuing goals of listening and guiding patients in their needs for reassurance and knowledge.

The main levels identified for the promotion of people's Sense of Grip on the basis of the three Profiles—as well as the objectives that the healthcare relationship has to set in relation to them—can be promoted through differentiated settings of psychological interventions:

- Individual and group counseling interventions addressed to patients, their caregivers, and families.
- Training courses for doctors, through workshops and ad hoc supervision.
- Consultancy interventions addressed to the healthcare relationship itself as a whole, through the participation in the medical examination of the psychologist as a catalyst and facilitator of dialogical processes (Freda & De Luca Picione, 2017a, b; De Luca Picione & Freda, 2014; Dicè et al., 2016).

Note that in the light of our considerations, developing a sense of grip on the part of the patient does not imply a destructive action of the constitutive asymmetry of the medical relationship, of the denial of scientific evidence in favor of subjective instances only. It is necessary to recognize the importance of the relational asymmetry (in terms of knowledge and positioning) between doctor and patient, of the ability to treat uncertainties, of the doctor's safety and directivity needs and correspondingly the patient's need for trust and search for reassurance. The development of the sense of grip is not in the direction of the symmetry of the relationship (in which the decision-making powers of the doctor and the patient come to collide and to clash) but in the direction of *participation*, *dialogue*, and *comparison*, putting into words feelings, expectations, uncertainties, disappointments, and hopes for the purpose of a participatory construction of consensus in therapeutic planning.

Conclusions

The clinical implications aimed at promoting SoGoD have been developed keeping in mind not only the needs of the person in her subjective relationship with the disease but also the objectives that may be achieved by the doctor–patient relationship in support of SoGoD from a systemic perspective.

The construction of SoGoD implies the transformative and dialogic dynamics of the relationship, rather than constructing a static representation of it as constituted by well-defined rules and behaviors (De Luca Picione et al., 2019a).

In this sense, from a semiotic-dynamic and systemic perspective, the sense of grip finds fundamental elements for its development within the healthcare relationship itself, family system, and each social context of interaction.

In summary, Sense of Grip on Disease shows gradually the development of new skills and new forms of:

(a) participation and sharing in strategic choices for the life of patients and their families;
(b) setting up joint-listening settings where both medical and psychological voices can dialogue;
(c) adequate training for doctors, to promote the development of healthcare engagement;
(d) and ability to narrate one's experience and interact dynamically with different interlocutors.

It is a question of development in terms of flexibility, variability, and integration of the semiotic capital (Salvatore, 2016, 2018) available for each healthcare context and its participants, that is to say, to develop and expand the degrees of possibilities of sensemaking processes.

The consideration of affective dynamics in a semiotic way implies that it is not possible to treat healthcare processes through the description of precise organizational and protocol lines of the intervention setting. Rather, it is necessary to refer to methodological and orientation functions that can then assume specific organizational formats in view of the contexts and specific problems.

The sense of grip proceeds through an "*oscillating trend between thinking and doing*" (Freda & De Luca Picione, 2013, 2017a, b). Gradually, it is possible to negotiate transformations of the same practices and/or the introduction of new practices useful to support an integration of psychological functions with reference to contexts, aims, resources, and constraints. In this scenario, the development of the sense of grip takes place in the forms of narrative mediation between the logic of medical discourse and the logic of the psychological perspective.

Supporting the sensemaking process of the illness experience as a development process does not imply a relationship of mutual exclusion and/or impediment between the logic of medical intervention and psychological intervention but the search for a contextual integration of the two perspectives.

In terms of the expansion of the semiotic processes, it is important to note that the development of the sense of grip consists in changing and increasing the degrees of freedom through which the experience is interpreted. Namely, a person is able to choose many options for her life.

The desired result does not focus on good or bad preordered representations of outcomes, but on the reduction of automatic and protocol forms of evaluations in order to pursue autonomous, broader, and more flexible forms of sensemaking for contextual purposes that can be defined in a shared and participatory way. Then in this scenario of gradual semiotic expansion, the conditions of disease, health, and well-being lose their hypostatized value and are transformed into articulated constructive processes able to achieve goals and to deal with the critical passages of this process.

The purpose is to leave the general and static categories of illness, health, and well-being in order to be able to find concrete, singular, and contextual forms without this implying an impoverishment of the subjective experience but rather enhancing the value of the idiographic aspect of the construction of new ways of relating and the gradual development of autonomy and self-responsibility.

In the narrative terms of the sense of grip, we remember that the risk of stiffening and reducing flexibility of one's own experience within contexts is intrinsic to the condition of chronicity itself. In contemporary scenarios in which chronic conditions are increasingly widespread and growing, the recognition of these semiotic dynamics takes on a strong relevance and becomes strategic in ethical, psychological, social, political, and economic terms.

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Chapter 10

A Patchwork of Good Intentions: A Critical Look at Different Perspectives Regarding Ethics-Based Mental Health Care in Under-Resourced Settings

Birthe Loa Knizek, James Mugisha, Eugene Kinyanda, and Heidi Hjelmeland

> The fundamental truth of global mental health is moral: individuals with mental illness exist under the worst moral conditions (Kleinman, 2009, p. 603).

Introduction

In 2001, the World Health Organization (WHO) proclaimed a "global burden of mental disease" and estimated 450 million people worldwide to suffer from some kind of mental or brain disorder at any given time (WHO, 2001a). Simultaneously, they launched "The World Health report 2001—mental health: new understandings, new hope" and set mental health as a global priority. Therein, they also pointed out the inequality of mental health care as over 40% of countries did not have any mental health policy and over 30% did not have any mental health program (WHO, 2001b). Following these alarming numbers, a series of articles during the years 2001–2007 in *The Lancet* set the agenda for the *Global Mental Health Movement* (GMHM): "No Health without Mental Health" (Prince et al., 2007). During the last two decades, the *Global Mental Health Movement* was developed further based on idealism and the

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urge for a communitarian social justice as well as human rights, demanding more mental health care and easy access to such in low- and middle-income countries (LMICs). GMHM is described as "…a movement with proponents, adherents, opponents, an ideology and core activities. Like all movements, it has leaders, meetings, publications, websites and a level of organization allowing it to function and expand" (Whitley, 2015, p. 286). GMHM views mental health care generally within a biomedical model and links it to existing development goals in low- and middle-income countries (LMICs) (Gajaria et al., 2019). In GMHM, ethics-based practice equalizes evidence-based practice with a Western origin. This has mobilized numerous critics (for example Mills and Fernando, 2014), whose arguments might have its own drawbacks. A more detailed description of the different positions follows below. Both sides might be and have been accused of ethical imperialism despite the underlying good intentions and therefore critical reflection is inevitable. This was, in fact, advised by one of the central figures in GMHM: "Self-reflection is essential to the improvement of the practice of global mental health" (Patel, 2014, p. 786). White et al. (2017) equally underline from their more sociocultural position how crucial critical reflection is for GMHM to avoid becoming a hegemonic approach. However, in order to understand the good intentions and ethical claims of both GMHM and its critics, it is necessary to take a quick look at the historical background.

The Historical Basis

Historically, mental illness has received very low priority in the developing world, which can be related to colonialism:

> In the colonial era, formal health care was unjustly distributed, often focused on ensuring the health and well-being of colonial administrators and European settlers. The health care of the indigenous population was a secondary interest to the medical establishment, unless it endangered white hegemony or social stability (Whitley, 2015, p. 286).

Even after decolonialization the neglect of mental health persisted, partially because other life-threatening problems, such as infectious diseases, war, natural disasters, famine, and drought needed attention (Whitley, 2015). In light of these pressing issues, mental health was neglected by both governmental and nongovernmental organizations (NGOs). Before the twenty-first century, the Global North was not especially interested in mental health in LMICs, and most of the efforts were directed towards the reduction of communicable diseases. Being somewhat successful in this endeavor, the noncommunicable diseases consequently appeared as a large proportion of the total disease burden (Alonso et al., 2013), and through this, mental problems shifted status from being peripheral to becoming a priority, as shown by their incorporation in the UN's Sustainable Development Goals, where Goal 3 "…seeks to ensure health and well-being for all, at every stage of life" (https://sdgs.un.org/goals).

However, according to Cherepanov, the beginnings of GMHM started out fragmented and were carried forward by voluntary mental health professionals with global interests, who were "…equipped with little but good intentions" (Cherepanov, 2019, p. 14). However, the development moved forward along increasingly egalitarian ideals. From the colonial era's mere focus on the health of the rulers at the end of the nineteenth century, the discovery of the "doctrine of uni-causality" (Kirmayer & Pedersen, 2014, p. 761) resulted into tropical medicine, where one now acknowledged that one germ could cause the same disease in both poor and wealthy people and rank was unimportant. With the emergence of the public health field, the attention was directed towards the "control or elimination of specific diseases in specific populations" (Kirmayer & Pedersen, 2014, p. 761), where Western models of both primary and secondary prevention as well as drugs were exported to non-Western settings. On this basis, the field of international health came into existence: "International health was largely framed in terms of the delivery of biomedical services modeled on urbanized Western medical practices, disease prevention, and therapeutics" (Kirmayer & Pedersen, 2014, p. 761). In recognition of the effects of globalization transcending national boundaries one at the millennium turn experienced a major paradigmatic shift into "global" health, thereby aiming at inclusion of populations all over the globe, irrespective of their income level, location, or nationality (Kirmayer & Pedersen, 2014). Thus, the outset of global health and its offspring GMHM was egalitarian and based on the idea of social justice in health.

Consequently, GMHM has worked in a linear fashion by first documenting the high burden of mental disorders in LMICs, second by arguing that mental disorders should be given high priority due to the economic burden they represent, third by addressing the relative gap of treatment services in LMICs, and finally by identifying and scaling-up evidence-based interventions by "task-shifting" in order to meet the treatment gap (Kirmayer & Pedersen, 2014). Task-shifting, or task-sharing, implies that lay workers are trained to take over some of the functions of the specialists, who are scarce in numbers in LMICs (Gajaria et al., 2019). GMHM advocates for mental health as a human right and is thus in line with the UN, who established the Commission on Human Rights in April 2002 and in 2005 renewed the mandate of the Special Rapporteur, who demands the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (UN Human Rights Council, 2017).

Universal Justice: Different Contexts

With the proclamation of mental health being a human right, apparently an ethical basis underlies the efforts of the UN, WHO, and GMHM. Still, it is important to clarify what the right to mental health contains. The UN operates with the following definition of health in general:

> The right to health is an inclusive right, extending not only to timely and appropriate health care, but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health. The right to health contains both freedoms and entitlements. Freedoms include the right to control one's health, including the right to be free from non-consensual medical treatment and experimentation. Entitlements include the right to a system of health protection (i.e., health care and the underlying determinants of health) that provides equality of opportunity for people to enjoy the highest attainable standard of health.
>
> (https://www.ohchr.org/en/issues/health/pages/srrighthealthindex.aspx)

The right to health is global and goes beyond an appeal for LMICs only. It is also more than a mere right to health and includes the determinants of health and in case of mental health especially the social determinants of health, which are forces beyond the individual. UN's Special Rapporteur for the right of everyone to the enjoyment of the highest attainable standard of physical and mental health underlines this point, when he suggests that the crisis in mental health should not be managed as a crisis of individual conditions, but as a crisis of social obstacles that hinders individual rights. Consequently, mental health policies should address the "power imbalance" rather than a "chemical imbalance health" (UN Human Rights Council, 2017) and the social determinants of mental health gained priority in the debate. As one of the central figures in GMHM, Vikram Patel also emphasized "...the simultaneous need for social interventions alongside biomedical interventions as appropriate for the individual" (Patel, 2014, p. 782). However, concerns were raised about the balance between social and medical influences on mental health (White, 2013; White et al., 2017). In addition, the initial definitions of social determinants of health were heavily criticized (for example, by Mills, 2014) for being limited and "individual-oriented materialistic" (Das, 2011). Since then, WHO changed the definition of social determinants into something more all-embracing and is now "...the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities—the unfair and avoidable differences in health status seen within and between countries" (https://www.who.int/social_determinants/sdh_definition/en/).

This universal definition now is so wide that one, in short, can describe it as a description of context or "life," since nobody lives in a vacuum. One is tempted to compare the WHO definition of social determinants with the humorous definition of life as a sexually transmitted disease with a mortality rate of 100%.

Furthermore, Fernando Lolas emphasizes how limited the reliance on a human rights position can be as one, in addition to accepting these rights, has to consider how they are ascertained and understood or how one can honor claims to entitlement (Lolas, 2016). In his view, we have two strands of justice where one is individualistic, while the other is collectivistic and based on common good considerations. Each of them is, however, violated often and in various ways. He therefore suggests replacing the demand for human rights with an "universal declaration of human duties," which by necessity would "...incorporate the duty to solidarity and reciprocity in human relations, irrespective of geography, culture, and socioeconomic status. Ours is a world of 'moral strangers' and 'epistemic strangers'. Humans do not believe in the same things and understand them differently, even if similar words are used" (Lolas, 2016, p. 13). The goal, according to Lolas, must be to create an integrative language, which overcomes linguistic and technical juxtapositions and recognizes the necessity of diversity in the context of universal humanness (ibid). He underlines the importance of the full recognition of the existence of different groups and that distinctions sometimes might differ and be arbitrary. With this contribution, he is in line with the critics of GMHM who are concerned about an inherent "cultural imperialism" (Miller, 2014). In his demand and critique of GMHM, Lolas seems close to, for example, Levinas (1985) and his reflections of the impossibility of knowing the other through oneself and only by the face-to-face meeting, where differences ideally can be recognized with enormous efforts. Proximity ethics apparently is at work in the background of Lolas' critique of the universality of the human being and perception of mental ill-health.

Universality: Dissimilarity

Despite the good intentions from GMHM, it has attracted heavy criticism as being a form of neocolonialism where flawed Western constructs of mental disease with an assumed physiological foundation are perceived to be universal and exported to LMICs to the detriments of its recipients (Stein & Palk, 2020). Even though GMHM mentions the importance of the social determinants of mental health, they seem difficult to combine with the assumption of the universality of mental diseases. According to, for example, Whitley (2015), many sceptics claim that GMHM is "… colonial medicine come full circle, a modern day version of Kipling's 'White man's burden', full of good intentions, but also a form of anthropologically uninformed cultural imperialism" (Whitley, 2015, p. 289). Kirmayer and Pedersen (2014) describe the concern of the application of Western concepts to other contexts like this: In the urgency to address disparities in global health, one forgets the many different ways that society and cultural context shape illness experiences and frame the problems. Thus, one intervenes in a way that is not culturally consonant, which likely might cause negative effects in the local population. Immediately after the authors have described these concerns, they suggest that the tensions actually may be between "armchair critics" who are not in a situation where they are confronted with people in need, and professionals who uncritically apply a framework that is insensitive to the context and promotes professional power and authority (ibid). This could seem like an attempt to mediate by taking out the sting of the dispute. However, the crux of the matter remains and can be summarized in the following questions: What is a mental disorder or disease? Are culture and context ignored through assumptions of universality?

Conceptions of Mental Disease or Disorder

According to Stein (2013), the nature of "mental disease or disorder" is placed at the heart of the philosophy of medicine and psychiatry. The ongoing debate on this provokes strong reactions as it draws in unavoidable principal questions: "Ontological as well as ethical questions come unbidden when dealing with the causes and meanings involved in mental illness" (Stanghellini & Rosfort, 2015, p. 323).

According to, for example, Kendler et al. (2011), mainstream psychiatry is essentialist, informed by positivism, and consequently aims at operationalizing definitions, which then influence the psychiatric classification systems DSM (Diagnostic and Statistical Manual of Mental Disorders) and ICD (International Classification of Disease). Kendler et al. (2011) state that the essentialist perspective assumes to meet phenomena that are independent of human classificatory systems and "real," but that this "comforting and satisfying" perspective has difficulties in accommodating sociocultural diversity and flexibility. The assumption of the transferability of the diagnostic systems produced in the West to different contexts has evoked strong negative emotions since this is perceived as a demonstration of a reductionistic view of the human being: "This universal psychobiological human is no more than a reductive caricature, an intellectual embarrassment" (Summerfield, 2012, p. 6).

At the opposite extreme, we find the constructionists who state that phenomena cannot be understood apart from the sociocultural networks in which they are embedded, while (genetic, physiological, psychological) factors that are shared between particular cases might be overlooked (Kendler et al., 2011). As mentioned above, the classification systems of mainstream psychiatry employed by the GMHM attract heavy criticism from this perspective. For example, the psychiatrist Summerfield (2012) describes diagnostics to be as much alchemy as science in that the declaration of a mental disorder is based on the observation of sufficient phenomena at sufficient threshold. The problem here is that the mental categories or diagnoses, which people are classified into, emerge as decisions from committees on clustering of certain symptoms. The classification systems change considerably for each edition of the manuals, as a group of people decides what is in or out, which then will have effects on the fate of myriads of people: "From a critical perspective, a psychiatric disorder needs to be understood as merely a social convention. Much as the definition of a weed varies from time to time, and place to place, so any particular disease or disorder is bound to a particular geographical and historical context" (Stein & Palk, 2020, p. 9). While scientists like Stein and Palk (2020), and Kendler et al. (2011), spend a lot of energy trying to solve the question of what a psychiatric disorder rendering justice to both biology and culture is, they fail to take a closer look into the implicated notions of personhood, which is crucial in order to avoid a construction of a human being similar to the reductive caricature that Summerfield (2012) described.

The Universal Person

Summerfield (2008) and Mills (2014), among others, claim that GMHM imposes a Western understanding of personhood, which might be quite alien in settings different from the West. Personhood, however, is a concept difficult to define. Still, it is used in a wide range of areas as for example legislation, politics and philosophy. In anthropology, it is an analytical term used to indicate whether a person can be considered to be a fully functioning and accepted member of adult society. In other words, personhood requires the recognition and acceptance by others and is consequently a psychosocial phenomenon. Stanghellini and Rosfort point out that personhood is both an experiential fact and an ethical problem in the area of psychiatry as well as in everyday life, and they state that "…personhood is a normative notion. To be a person may be a fact, but it is also a task" (Stanghellini & Rosfort, 2015, p. 320). It is a task since we are human beings in a context with specific normative guidelines, which we, in one way or another, have to aspire to in order to be recognized and accepted as a person. This is an ongoing struggle or task as both the context and the human being are in constant change:

> The fact that I am responsible for the person that I am, not only for what I say and do, but also for what I feel and think, makes being the person that I am a task that very easily becomes a burden.(…) To be able to live with who I am, I have to make sense of and try to cope with what I care about in the light of the norms that make up my life as a person. This means that being a person implies a never-ending task of self-disclosure and self-interpretation (op. cit., 329–330).

Consequently, it seems a fatal flaw to assume a universal humanness since one must include an understanding of the sociocultural expectations of personhood and the person within a given culture and its inevitable consequences for the entire biopsychosocial system. Wellness and suffering, which are experienced individually and are fundamental to our health, must be understood on the background of the specific context in which the person is living. The living conditions differ greatly for human beings in interdependent and independent societies; while a person in the West ideally must develop into independence, a person in interdependent societies has other struggles regarding social relationships that massively influence health and well-being. This means that not only do the social determinants of health differ due to different living conditions and normative contexts but so do the experiences of illness (physical and mental). Ikuenobe (2022) provides a convincing description of the African notion of personhood (in relation to suicide prevention) and shows how the community as a catalyst and prescriber of norms plays a vital role in the acquisition of personhood. He bases his description of the African notion of personhood on Gyekye (1984), among others, who elaborates on how the Akans "…maintain a thorough interactionist position on the relation between soul and body: They believe that not only does the body have causal influence on the soul but also the soul has causal influence on the body (*honam*). What happens to the soul (*okra*) takes effect or reflects on the condition of the body. Similarly, what happens to the body reflects the condition of the soul" (Gyekye, 1984, p. 209). According to

Ikuenobe (2022), this means that health for a person requires not only harmony between biological and psychological-metaphysical aspects but also a harmonious relationship with others in the community and the superior social moral context. Consequently, mental health and disorder only can be understood by means of these dynamic relations, and the pathologization of an individual would be a gross mistake. Biology's significance is not denied but is what "...predisposes us to be social-moral beings" (Ikuenobe, 2022, p. 11).

Interestingly, the African ontology, to a large extent, assembles the ideas that can be found in Europe's psychosomatic medicine (Von Uexküll & Wesiack, 1988), where one states that the body does not stop with the skin as the environmental experience (Umwelt) and the body represent an indivisible unity of a system: "The crises to which a person is exposed in the course of his development change him and his world. These crises can be read off the structure of the human system" (Von Uexküll, 1972, p. 419). Experiences, from this perspective, put the body into states of readiness, which influence the development of the body and can cause severe damage. In other words, the body develops and reacts to external influences and consequently is personalized and not universal.

The discussion goes on and is studied in depth from a philosophical standpoint by Thornton (2017). Especially since there does not seem to be any final "solution" in sight, careful reflections on ethical claims against the existing body of knowledge that underly actions affecting people must be routine both among the most "conservative" GMHM supporters and among the enthusiastic sceptics. Ethical imperialism must be avoided and attempts to alleviate the tensions are already made.

Differential Ethics

During the last 30 years, the effects of culture on to the principle of bioethics have been studied and discussed. Chattopadhyay and De Vries (2008) argued that systems of bioethics should be suited to, and situated in, local culture, and they claim an existing moral imperialism of Western bioethics (Chattopadhya & De Vries, 2013). They state that "...for some Western bioethicists, culture appears to be an enigmatic puzzle. Sometimes it is seen a barrier that needs to be overcome to provide 'scientific' health care (...). But cultural diversity is something that cannot be denied or opposed: it is simply a fact of life in our world" (Chattopadhya & De Vries, 2013, p. 4). They further argue that one has to consider the actual context with individual and collectivist values, and this means that in real-life situations, one is confronted with the possibility that "...there is more than one way to do things right" (ibid, p. 6). They do not argue for ethical relativism but oppose the uncritical transfer of individual-centered bioethics as the foundation for healthcare as moral imperialism, and they claim that respect for cultural diversity is an ethical imperative. The question is how to navigate between the abysses of universality and relativism.

In the 1990s, the German bioethicist Hans Martin Sass developed the concept of differential ethics, where he is especially focused on the relationship between patients and professionals (Sass, 2006). Ethicists involved in GMHM, and the ongoing debate around it, have discovered the potential of his work, and, for example, Lolas Stepke (2015) recommends transferring Sass' reflections into the GMHM area. Sass developed models and interaction guides in which the focus is on establishing a partnership between those who provide and those who receive health care that goes beyond traditional, paternalistic models. Sass consequently upgrades the values and preferences of the patient, which vary in different contexts. For him, this is an advantage, since "… conflicting positions and visions in bioethics will be able to use different cultural experiences and traditions of moral intuition in a communication-in-trust and cooperation-in-trust attitude for the sake of the patient and of those who suffer and are in need of help and support of life and support of love of life" (Sass, 2004, p. 4).

Fulford and van Staden from the Collaborating Centre for Values-based Practice (Oxford University) develop Sass' thoughts further by promoting the development of value-based clinical skills. Values are here defined as "…anything that matters or is important from the perspective of the person concerned" (Fulford & van Staden, 2020, p. 19). In their argument, evidence-based practices are not enough as they do not consider the individual's life goals or values. They differentiate between a Fact-only model and a Fact-plus-Value model, where the latter is a moderation of evidence-based practice. In their opinion, their model is inclusive of both science as such and of cultural diversity and their influence on healthcare:

> In a Fact-only model the challenge is how to incorporate values (including cultural values). In a Fact-plus-Value model the values are there already. So, there are no dilemmas of as (…) "on the hand…and on the other hand". Both "hands", as it were, are there already. With the left hand (of facts) we hold on to the psychobiological mechanisms of contemporary psychiatry. With the right hand, we hold on to culturally appropriate services (to the extent that this means services that respect differences of cultural values) (Fulford & van Staden, 2020, p. 29).

In this Fact-plus-Value model, the healthcare receiver must be a partner, like in Sass' model. They are aware of the differences of values in independent and interdependent contexts, the contextual variations of social determinants, and the necessity of considering health beyond the individual. But they never question a possible Western bias in evidence-based practice, which assumes the universality of the human being and is one of the main subjects of criticism among the sceptics. However, others have worked on alternatives in order to bypass the most severe issues in the debate.

Attempts to Avoid the Trench Warfare

Kendler et al. (2011) present a practical instrumentalist/utilitarian approach as an alternative to traditional biomedical-based models. According to them, the more pragmatic practical approach takes what each of the sides offer and does not get "sidetracked into debates about metaphysics" (Kendler et al., 2011, p. 1146). In plain text, they claim that if the core problem of the perception of mental disorder in the classification systems cannot be solved, we should get rid of it and build something new from scratch. Their suggestion is the mechanistic property cluster (MPC), which defines mental disorders "… at the level of property clusters under-girded by dysfunctional but self-sustaining mechanisms" (Kendler et al., 2011, p. 1149) and can be applied to all living mammals. On the basis of the occurrence of properties (psychological or biological) and their interaction without referring to an underlying essence or cause, it is possible to make projective inferences and predictions. According to their model, illnesses will appear as more or less stable sets of traits. In the absence of enough knowledge about the brain, they suggest this more pragmatic approach, where a notion of personhood is nonexistent, and the focus is on a set of traits that are mutually interacting. This theory is perceived as a waiting position in the quest for a final neurological explanation. It seems that we here are not only caught up in the never-ending discussion of a mindless brain versus a brainless mind but with this approach also in a mindless as well as a brainless collection of traits.

Others, for example, Metzl and Hansen (2014), have tried to solve the shortcomings of the existing rigid diagnostic systems in the meeting with a many-facetted clinical reality by demanding an increased "structural competence" to understand the influence of contextual factors on the individual and the health setting. Instead of a pragmatic approach, like the one proposed by Kendler and colleagues, they choose to plead for a systemic, dynamic understanding mixed with elements of Levinas' (1985) proximity ethics. Professionals are increasingly trained in cultural competence in order to be able to identify the cross-cultural expressions of illness and health. The societal factors or social determinants of health and the health setting are, however, ignored (White et al., 2017). In their response, Metzl and Hansen state that "…stigma and cultural conflict in health-care settings need to be understood as the sequalae of a host of financial, legal, governmental, and ultimately ethical decisions with which medicine must engage politically if it wishes to help its patients clinically" (Metzl & Hansen, 2014, p. 127). While Metzl and Hansen focus especially on the heterogeneous population with drastically different living conditions in the US, their approach also might be of more global interest (Gajaria et al., 2019). They suggest to replace cultural competency with structural competency in order to counteract medical educations' "over-competency syndrome" and make it possible to recognize how "…'culture' and 'structure' are mutually co-implicated in producing stigma and inequality" (ibid, p. 128). Their model of "structural competency," which they call paradigm, is shaped by five intersecting skill sets:

(1) Recognize the structures (economic, physical, sociopolitical) that shape the clinical interaction and impacts on medical decisions. (2) Develop an extra-clinical language of structure by "imparting fluency in disciplinary and interdisciplinary understandings of structure as they pertain to illness and health in community settings." (3) Rearticulate "cultural" presentations in structural terms on the background of the terms and concepts in the interdisciplinary literature. (4) Observe and image structural interventions as structures change over time and are dynamic.

(5) Develop structural humility and recognize the limitations of structural competency (Metzl & Hansen, 2014, pp. 128–131).

Structural competency is an ambitious and comprehensive approach that "…enables clinical practitioners to bridge the microprocesses of their interactions with patients with the macroprocesses of population-level inequalities that often determine their patients' mental health outcomes" (Metzl & Hansen, 2017, p. 116). With their approach, they are close to Kirmayer and Pedersen who emphasized that GMHM as a cross-cutting area involved this form of structural competency exploring historically and socially produced health inequalities. This involves how "…political and economic structures are embodied in illness experience every bit as much as are early family experience and biology"(Kirmayer & Pedersen, 2014, p. 767). With a failure to incorporate the cultural, social, political, and economic realities, the gap between the rich and the poor will continue widening, with huge health consequences including mental health (Kirmayer & Pedersen, 2014). This approach implies collaboration with other groups and political activism in order to change unhealthy conditions and effectuate structural interventions (Gajaria et al., 2019). From the mere proclamation of mental health as a human right, these researchers pave the way for health professionals to become activists in order to attain the goal of universal justice.

Interestingly, some problems remain the same. For example, Metzl and Hansen (2014) acknowledge the importance of getting the diagnosis right, and they believe that a clinician with structural competency would possess skills of differential diagnosis and avoid short circuits where incomprehensible clinical phenomena are explained by means of culture, ethnicity, or similar. With their model or paradigm, they aim at contextualizing the clinical encounter and diagnosis, but they never question the category system or its universality as such. Their approach is ambitious and idealistic, which implies that clinicians engage in and understand the impact of sociopolitical and normative forces on their patients and themselves, but some central questions remain untouched. Implied in this dispute is the notion of the human being and the nature of mental health, which in structural competency is framed as "…a state we strive for in our daily lives, and as a larger organizing principle for social justice, community betterment, and institutional change" (Metzl & Hansen, 2017, p. 116). Structural competency is an approach that broadens the view of the health professionals and instructs some activism. However, the retention of the diagnostic system implicates the question of whether we are dealing with a "universal psychobiological human" (Summerfield, 2012) that can be approached with standardized measures as an ethics-based practice. While Patel insists on the evidence-based practice as the way forward and "…irrational and inappropriate interventions should be discouraged and weeded out" (Patel, 2011, p. 1442), others have tried different ways.

Beyond the Diagnostic System

With Welfarist psychiatry, Roache and Savulescu (2018) developed a theoretical framework with the intention to displace the diagnostic system based on the current paradigm. As Kendler et al. (2011) mentioned earlier, they aim at avoiding the risk of entrenching flawed aspects of Western psychiatry in new populations and the neocolonial imposition of Western mental health norms, as well as reducing stigma towards mental illness and prevent the abuse of psychiatry for immoral or political purposes. They state that there is a danger that Western psychiatry incorrectly pathologizes, misdiagnoses, overdiagnoses, and overtreats (McConnell & Savulescu, 2020). The ambitions for their own approach are high:

> Welfarist psychiatry corrects these significant flaws in the Western psychiatric model, avoids neocolonialism by indexing aspects of patient welfare to the local sociocultural context, reduces stigma by abandoning the concept of "normal" mental health, and provides grounds to restrict the misuse of psychiatry by appealing to objective aspects of personal and social well-being (McConnell & Savulescu, 2020, p. 37).

Instead of going into a dispute, this approach dismisses the diagnostic system entirely, but in contrast to Kendler et al. (2011), McConnell and Savulescu contain a notion of a person in their model. Welfarist psychiatry has left the concept of mental disorder and replaced it with psychological disadvantage (PD), which they describe as a stable psychological trait that "...tends to worsen well-being given the social and environmental context. PDs do not necessarily form part of a syndrome, involve no threshold between health and dysfunction, may include socially deviant behavior and are not wholly attributable to the individual's 'underlying mental functioning' because they involve a mismatch with the environment" (McConnell & Savulescu, 2020, p. 38). This definition implicates that each of us has different PDs where an enhancement would improve our well-being. For example, in a specific setting shyness with regard to speaking in public or to the media might be a PD for some people, while impulsivity or stubbornness might be a problem for others. Consequently, PDs cannot be understood without the context, as it is the interplay between the person and the context that makes up the PD. When there is a mismatch between a person's mental traits and his/her environment, we are facing a PD, which makes the debate on the "essence" of mental illnesses irrelevant and consequently the entire debate on the universality of the human being outdated. While GMHM also advocates for the empowerment of patients (Kleinman, 2013), Welfarist psychiatry is based on the first-person perspective: through the experience by a person and his/her ideas of a good life, is it possible to decide on what measures might be necessary to enhance well-being? But McConnell and Savulescu (2020) admit that one also must have "objective" reflections as personal means and values for well-being might conflict with either their social context or their ability to achieve their goals. Welfarism is about the enhancement of well-being irrespective of the outset, but with a social justice basis, and the more severe cases of PD would be prioritized. Because of the width of the PD category, it is possible to think broader than psychiatric treatment, which sometimes might even be an inappropriate response. For example, in settings that are strongly oppressive, it might be more appropriate to work with the context than adjusting the individuals to the situation through treatment. Another situation might be where poverty and unpredictability have severe consequences for the well-being of people. Here, the work for better living conditions, safety, and stability might be more fruitful than psychiatric treatment; PDs may be treated "...by addressing one or more of the biological, psychological, and/or sociocultural factors that contribute to a person's having a PD" (McConnell & Savulescu, 2020, p. 45).

However, to recognize these sometimes-intricate relationships of forces, one would need the structural competence that was described earlier (Metzl & Hansen, 2017), which the welfarists never mention. The welfarists in their eagerness to avoid the pitfalls that follow the Western category system, like Metzl and Hansen (2017), presuppose exhaustive insights of health-care professionals, but realize their limited political power and acknowledge that they are "...better placed to intervene at the level of the individual rather than the individual's sociocultural context. However, Welfarist psychiatry doesn't make the bioreductive assumption that PDs develop exclusively at the individual level and so are problems only for, or related to, the individual. So, if certain political policies are causing PDs, Welfarist psychiatry can highlight that publicly and can let individual patients know when their PDs are significantly caused by sociopolitical factors" (McConnell & Savulescu, 2020, p. 48). This means that welfarists must first be able to see through the intricate relationship of involved forces that influence an individual's living conditions and then tell the individual that he/she is not to blame because of these forces. A timely question here would be whether it actually is a good idea to tell individuals that they are caught up in a hopeless situation beyond their control. Maybe they realize that their PDs are not their "fault," but on the other hand, it can reinforce the feeling of helplessness and thus increase hopelessness. It might seem that Welfarist psychiatry, despite high ambitions and good intentions, still has some issues to solve when it comes to transferring the theoretical frame to clinical practice.

Concluding Remarks

On our way through GMHM, their critics, and their attempts to overcome some of the most fundamental problems, we have seen nothing but good intentions and ethical claims of communitarian justice. Everybody agrees that mental health is a human right but disagrees on what health and right, respectively, are about. One might even go as far as Lolas (2016) and abandon the human right as worthless and replace it with a demand for "universal human duties." Implicated in the entire debate, which appears partly emotional as well as moralistic, is the question of what a human being is, both understood as personhood and as a biopsychosocial entity. We have seen attempts to bypass this question in expectancy of the neurological final explanation by a utilitarian approach in mechanic property clustering (Kendler et al., 2011), where the notion of the human being has disappeared, but they offer an alternative diagnostic system. In the same direction, welfarist psychiatry abandons the Western diagnostic system entirely and introduces a dynamic concept, psychological disadvantage, which is the mismatch between an individual's psychological trait and the context resulting in reduced well-being. This provides the opportunity to employ more tools in mental health care than only medical ones. One aim is, for example, to clarify for the patient what is beyond his/her control but without explicating how health professionals should have specific competence in seeing through the intricate relationships of forces on the societal level. The demand for structural competency (Metzl & Hansen, 2017), on the other hand, focuses especially on forces beyond individuals that determine their situation and implicates some activism from the health professionals. This model is ambitious and idealistic aiming at providing better skills for differential diagnosis and consequently accepts the Western diagnostic system and the problems following it. In both Welfarist psychiatry and the value-based practice (Fulford & van Staden, 2020), one tries to involve the affected person in the decision on relevant treatment. However, while the values-based practice works without reflecting on structural forces influencing the client's situation, the Welfarist psychiatry presupposes psychiatrists' reflection on these forces but without indicating how the professionals obtain this insight. This debate on central issues and attempts to go beyond it is more than being a struggle between "armchair critics" and professionals who meet people in need (Kirmayer & Pedersen, 2014). All are carried forward by good intentions to help and assist people in need with practices that are effective and ethically based despite limited resources and cultural differences. Together they appear as a patchwork of good intentions, where none of the single approaches seems to be able to solve the ethical, theoretical, and practical issues. Good intentions are not enough, and critical self-reflection must be at the basis of every action affecting other people. Patel's words of self-reflection as essential for the improvement of global mental health (Patel, 2014) appear to be crucial in the development of ethics-based practice.

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Chapter 11
Communal Moral Basis for Understanding Personhood, Health, and Suicide

Polycarp Ikuenobe

When 'I' is replaced by 'We', even illness becomes wellness (Malcom X—1925–1965).

Introduction

In this essay, I discuss African normative conception of *personhood*, to illuminate the nature of, and the need for, contextualized *ethical-based practices* in healthcare and suicide prevention. Suicide involves complex issues deriving from lack of material, physical, and psychological well-being, disharmonious relationships in a community, and a diminished sense of self-hood. The African conception indicates that a robust sense of *personhood* consists of social-moral aspects and bio-physical, psychological, and metaphysical aspects. The social-moral aspects involve the internalization of communal norms and moral principles, and using them to perform obligations, to achieve moral and psychological well-being, self-realization, general welfare, and harmonious relationships. I argue that this conception of personhood is relevant for understanding the issues of health, well-being, and suicide among Africans, and the important role that a community and relationships can play regarding wellness and suicide prevention.

I argue this point in the context of the findings (Knizek et al., 2011; Kizza et al., 2012) that many cases of suicide in Africa are the result of despair, hopelessness, shame, and a *diminished sense* of: physical health, material and psychological well-being, power, control, self-hood, social worth or standing, ability to meet one's obligation, and disharmony in one's relationships with others and one's community. A positive sense of *health and well-being* requires a robust sense of *personhood*: that

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is, being in *harmony* within oneself (psycho-physically), and in social-moral harmony, and solidarity with others in one's community. As such, one way to care for and ensure the health and well-being of a *person* is to understand all these aspects, one's lived-experiences, and social-moral situation that define one robustly as a *person* and one's well-being. This implies that a *person's* robust sense of health and well-being cannot be conceived of or addressed entirely in terms of bio-physical and psychological factors without considering social-moral factors. Thus, any decision regarding how to care for a *person* and ensure her health and well-being, including suicide prevention, must take social-moral and contextual factors into consideration, as well as biological and psychological factors and pathologies.

African Robust Conception of Personhood

There are different African conceptions of personhood. The first focuses on descriptive biological, physical, psychological, and spiritual features (Gyekye, 1984; Onwuanibe, 1984), and the second focuses on normative, social, and evaluative features (Menkiti, 1984). However, others argue that these two views represent two aspects of a robust conception of personhood (Gbadegesin, 1998; Ikuenobe, 2006), such that the descriptive features of a person provide the material conditions for the normative. Thus, one cannot be called a person in a "true sense," if one has not satisfied the normative criteria, but in order to satisfy the normative criteria, one must have the descriptive physical, biological, psychological, and metaphysical features. The normative aspect of personhood depends on the requisite descriptive features, which imply certain normative notions of rights and the duty of others to respect one's right, autonomy, life, and dignity (Iroegbu, 2005; Metz, 2012).

In this sense, *personhood* is a function of communal affirmation and recognition involving the positive moral evaluation of one's character and actions based on communal values and obligations. Such affirmation or recognition is a significant basis for others to morally ascribe "personhood" as one deserving of respect by others, which enhances one's healthy sense of self, dignity, and well-being. This conception indicates that "personhood," "health," "dignity," and "well-being" are *thick concepts* with an evaluative (social-moral) aspect and a descriptive (bio-psychic and metaphysical) aspect, and both aspects are essential for understanding these concepts. When one makes the statement, "Jane is not a *person*," it is not meant to be entirely *descriptive*, in terms of denying the descriptive natural, biological, metaphysical, or psychological features of personhood. The statement, "Jane is a person" involves the *bestowal* of a value, requiring a normative judgment that she has good character, behaved morally, acted properly, or has or feels a healthy sense of self or well-being, based on accepted communal values.

As Gyekye (1997) indicates, the normative conception of personhood is correct; if it is understood as a moral thesis, then it is relevant for understanding communalism in African cultures and the contextual social-moral basis for self-hood. In his words,

> The judgment that a human being is "not a person," made on the basis of that individual's consistently morally reprehensible conduct implies that the pursuit or practice of moral virtue is intrinsic to the conception of a person held in African thought. The position here is, thus, that: for any p, if p is a person, then p ought to display in his conduct the norms and ideals of personhood. For this reason, when a human being fails to conform his behavior to the acceptable moral principles or to exhibit the expected moral virtues in his conduct, he is said to be "not a person." The evaluative statement opposite this is, "he is a person" means, "he has good character," "he is peaceful–not troublesome," "he is kind," "he has respect for others," "he is humble." The statement "he is a person," then, is a clearly moral statement. It is a profound appreciation of the high standards of the morality of an individual's conduct that would draw the judgment "he is truly a person" (Gyekye, 1997, p. 50).

Such judgment assumes that individuals have the capacity for free choice, the cognitive abilities to internalize communal values and use them rationally to guide behaviors, in order to achieve affirmation, self-realization, well-being, and a positive and healthy sense of self. Moreover, one is expected to use the internalized norms to behave in ways that enhance general welfare, mutuality, solidarity, harmonious living, and relationships with others in the community.

African communalism and ethics are rooted in the tradition of a group of people with common kinship, aspirations, values, and beliefs, who are living together and organizing most aspects of their lives cooperatively in a community. This idea can be illuminated by Menkiti's (1984) idea of a *collectivist* community, as opposed to a *constituted* community. A *constituted* community is a simple aggregation of all individuals who *choose voluntarily* to be part of the community. African *collectivist* community, "collectivities in the truest sense" in Menkiti's words (1984, p. 179), is an organic group of individuals, relationships, values, cultural traditions, interests, and obligations that transcend individuals or their simple addition. Such community is not reducible to its individuals and institutions, because the community is not the simple addition of individuals and institutions. It involves transcendent social-moral norms and relationships that mold individuals' identity, character, conception of good, choices, preferences, and actions.

Communal values provide the basis for integrating individuals into communal harmonious living for their own well-being. This implies that a community's well-being depends on and supports individuals' well-being, and vice versa, and individuals' identity and healthy sense of self are dependent on, and relational to, communal relationships and solidarity. Communal well-being does not supersede or undermine individuals' well-being; they are coextensive and mutually supportive. The community enhances individual well-being and expands the scope of individual substantive choices and makes them meaningful or valuable by providing the material conditions and options of goods from among which one can choose.

Nyerere (1968) uses the idea of *Ujamaa* to articulate this *collectivist* idea of African community, its values, and structures of welfare, caring, mutuality, social relationships, responsibility, and harmonious living. He argues that: "In traditional African society we were individuals within a community. We took care of the community, and the community took care of us. . . . Nobody starved, either of food or of human dignity, because he lacked personal wealth; he could depend on the wealth possessed by the community of which he was a member" (Nyerere, 1968, pp. 165–166). The care, values, material goods, and harmonious conditions that the community provides give an individual a healthy sense of self, which engenders one's physical and mental well-being and health. Everyone in the community with the requisite capacity has the responsibility to contribute to communal welfare, to ensure that everyone is taken care of and healthy.

This idea of *Ujamaa* or communalism underscores the idea that issues of individual wellness, well-being, healthcare, and communal welfare are everyone's business and responsibility. This African idea is cryptically captured by Mbiti thus: "I am because we are, and since we are, therefore I am" (1969, p. 141). In one sense, this implies that "I" or self-hood is possible and meaningful only in the social-moral and cultural context of a community that helps one to achieve a positive and healthy sense of self, in virtue of which one is able to experience a sense of mental well-being and health.

Menkiti (1984) highlights the central point in Mbiti's (1969) aphorism about the African view of personhood by contrasting it with the Western view of the person:

> whereas most Western views of man abstract this or that feature of the lone individual and then proceed to make it the defining or essential characteristic which entities aspiring to the description 'man' must have, the African view of man denies that persons can be defined by focusing on this or that physical or psychological characteristic of the lone individual. Rather, man is defined by reference to the environing community (Menkiti, 1984, p. 171).

The Western conception of personhood involves the lone solitary individual, defined by certain physical-biological and mental characteristics that are removed from the social-communal context of human relationships. It sees individuals' health simply in terms of the absence of pathologies in bio-psychical conditions. On the African view, personhood and well-being are social-morally contextual, in that one's well-being, positive and healthy sense of self-hood, affirm and is supported by, one's "beingness together" or one's "beingness-with-others" involving "a mental commonwealth with others" (Menkiti, 2004, p. 324).

On this African conception of personhood, "it is not enough to have before us the biological organism with whatever rudimentary psychological characteristics are seen as attaching to it" (Menkiti, 1984, p. 172). Personhood, identity, and a person's health or wellness have social-moral elements. Lee and Hord underscores this view by saying: "Identity is not some Cartesian abstraction grounded in a solipsistic self-consciousness; rather, identity is constructed in, and at least partially, by a set of shared beliefs, patterns of behaviour, and expectations" (1995, pp. 7–8). Thus, for Menkiti, "the sense of self-identity which the individual comes to possess cannot be made sense of except by reference to these collective facts" (1984, p. 172) and it is the "rootedness in an ongoing human community that an individual comes to see himself as man" (pp. 171–172). The collective facts and ongoing human community that define persons, according to Menkiti, include communal gene pool, language, mental dispositions, and attitudes, by virtue of which one has harmonious relationship and solidarity with others in the community. Perhaps, Menkiti would allow for the possibility that immigrants can be fully integrated and assimilated into communal attitudes, values, beliefs, and practices, in order to maintain harmonious relationships, solidarity, and social-moral identity.

Language is an essential feature of a community's culture, values, and norms of human interaction that provide the basis for making meaning of concepts and lived experiences. Charles Taylor (1991) underscores the important role of language, in virtue of which humans form a meaningful sense of self-hood and have solidarity and harmonious relationship with others that enhance one's well-being and health. As Taylor indicates, "We become full human agents, capable of understanding ourselves, and hence defining an identity, through our acquisition of rich human languages of expression" (Taylor, 1991, p. 32). Communal relationships and solidarity are defined by a process of cultural, social, moral, and linguistic incorporation into the community, without which "individuals are considered to be mere danglers to whom the description 'person' does not fully apply" (Menkiti, 1984, p. 172). Thus, it is on the basis of one's cultural, linguistic, and social ritual incorporation into the community that one becomes a "full person in the eyes of the community" (Menkiti, 1984, p. 174).

We must understand this sense of self-identity broadly to include one's sense of social-moral-psychological health and well-being that derive from one's relationships and solidarity with others and communal values. In Wiredu's view, the concept of a person has a normative layer of meaning such that a person is not just an individual of (biological) human parentage but also one who evinces an adequate sense of social responsibility in one's actions and projects (1996). A person is a biological and social-moral organism. The African ideas of personhood and well-being, which are manifested in virtuous character traits, are acquired by organic constitution in, and by, a community (its values) through a process of acculturation. As an organism, a person develops progressively and actualizes the potentiality of one's biological nature and metaphysical capacities by participating in communal life and obligation and learning to use properly such capacities for one's own and general well-being.

As Menkiti indicates, "We must conceive of this organism as going through a long process of social and ritual transformation until it attains the full complement of excellencies seen as truly definitive of man. And during this long process of attainment, the community plays a vital role as a catalyst and as prescriber of norms" (1984, p. 172). Wiredu (1996) indicates that this process of integrating the individual into the community is so subtle and thoroughgoing that it is rarely noted. Because the focus of Western philosophical conception of personhood or identity involves metaphysical and not social-moral features, there is no emphasis on acculturation and ritual incorporation into the community and the internalization of its social-moral norms. The difference between this Western view and the African view that emphasizes social-moral features is implicated not only in the conception of personhood and health but also in the approaches to healthcare, wellness, and well-being. In African traditions, wellness and health is manifested in "personhood is the sort of thing which has to be attained, and is attained in direct proportion as one participates in communal life" (Menkiti, 1984, p. 176).

In Menkiti's view, the "human community plays a crucial role in the individual's acquisition of full personhood" (p. 179) in the sense that "the community plays a vital role as catalyst and as prescriber of norms" (p. 172). As he indicates,

> the transgression of accepted moral rules gives rise not just to a feeling of guilty but to a feeling of shame—the point being that once morality is conceived as a fundamental part of what it means to be a person, then an agent is bound to feel himself incomplete in violating its rules, thus provoking in himself the feeling properly describable as shame, with its usual intimation of deformity and unwholeness (Menkiti, 1984, p. 176).

The feeling of shame, deformity, incompleteness, and unwholeness creates disharmony within oneself and with others, absence of "moral arrival," a diminished sense of self, health, wellness, and well-being, which could engender suicide. According to Menkiti, "the notion of person is the notion of moral arrival, a notion involving yardsticks and gradations, or, more simply, involving an expectation that certain ways of being or behaving in the world may be so off the mark as to raise important questions regarding the person-status of their doers" (2004, p. 326).

The above point indicates how one's sense of self-worth, social value, dignity, and status as a person, affirmation, and respect by others in a community, which contribute to one's well-being and positive sense of self, derive from how one uses one's autonomy and other capacities to act in ways that conform to communal norms and expectations. Thus, according to Metz (2012), the "dignity of human beings emanates from the network of relationships, from being in community" (p. 26), such that "our dignity is constituted by our existing relationships with others" (p. 26). The African conceptions of "personhood" and "health," which involve harmonious relationships, solidarity, dignity, and self-realization, are implicated in the idea of *ubuntu*, the notion that *a person is a person through other persons*. This idea indicates that one achieves self-realization, a sense of worth, and a healthy selfhood by acting to promote communal harmonious human relationships. This African view suggests the importance of one's lived experiences in social-moral context and practices to one's health to necessitate ethical-based practices in healthcare.

Metz articulates the communal ethics of *ubuntu* in terms of the following principle: "An action is right just insofar as it promotes shared identity among people grounded on good-will; an act is wrong to the extent that it fails to do so and tends to encourage the opposite of division and ill-will" (2007, p. 338). This view involves a responsibility-and-outcome-based ethics involving the *use* of one's autonomy and rationality properly, to promote communal solidarity, caring, and harmonious relationships, in virtue of which one achieves personhood and a healthy sense of self. This *ubuntu* ethics that undergirds personhood, health, and well-being represents Frankena's (1963) hybrid ethics of "mixed-deontology." It is consequentialist by requiring that "persons" promote the utility of harmonious living, relationships, well-being, solidarity, and shared identity, and deontological, in that it requires duty, right action, justice, and good will.

An African Metaphysical View of Personhood and Health

Although the focus of African conception of personhood is its social-moral aspect, it does not deny the bio-psychic and metaphysical aspect, rather it presupposes the bio-psychic as that in which the social-moral inheres. In Gyekye's (1984) Akan philosophical psychology and metaphysical account of personhood, he argues that a *person* is made of the body (*honam*), spirit (*sunsum*), and soul (*okra*). Although the *spirit* and the *soul* are functionally different, in that they perform different mental functions, they are two different functional aspects of the same spiritual substance. In Gyekye's (1984) view, the spirit (*sunsum*), which is psychical, represents an individual's personality, character traits, qualities, feelings, thoughts, emotions, attitudes, dispositions, and desires, whereas the soul is the source of life, vitality, energy, and breath. The spirit (*sunsum*) embodies one's character traits and moral attitudes, which are shaped in part by one's context, social-moral norms, and communal relationships. One's spiritual health involves psychological or mental health, which depends on one's socio-moral character traits and dispositions that are shaped by healthy relationships with others.

The spirit (*sunsum*) is the entity in which psychological, moral, and social qualities inhere; thus, "moral attitudes are generally attributed to *sunsum*" (Gyekye, 1984, p. 210). These moral qualities and attitudes are manifested in one's behaviors and actions. According to Gyekye, "Personality and character traits of a person are the function of the *sunsum*. The *sunsum* appears to be the source of dynamism of a man, the really active part or force of the psychological system of man. . . . it is that which thinks, desires, etc. . . . In short, it is upon the *sunsum* that man's health, worldly power, influence, position, success, etc. would depend" (1984, p. 207). Since one's sense of health or well-being depends on *sunsum*, a diminished sense of health and well-being can be addressed by focusing on *sunsum*.

The spirit (*sunsum)* provides the metaphysical and psychological basis by which we account for the social-moral aspect of the robust conception of a person, as consisting of social-moral and psycho-physical elements. The metaphysical view of the person indicates a two-way interaction between the spiritual and physical aspects of the person, and an essential connection between the physical and mental health and well-being of a person. According to Gyekye, "The Akans, however, maintain a thorough interactionist position on the relation between soul and body. They believe that not only does the body have causal influence on the soul but also the soul has a causal influence on the body (*honam*). What happens to the soul (*okra*) takes effect or reflects on the condition of the body. Similarly, what happens to the body reflects the condition of the soul" (1984, p. 209). The conditions of the soul, body, and their interaction (which could be in harmony or disharmony) are reflected in the spirit (*susum*) and are then manifested in one's health, well-being, attitudes, behaviors, and dispositions.

When the soul or body is injured or enfeebled, it results in ill-health and a diminished sense of self and well-being, which are manifested in one's emotions, attitudes, general outlook, and then behavior. Gyekye indicates that this "belief in psycho-physical causal interaction is the whole basis of spiritual or psychical healing" (1984, p. 209). The relevance for understanding and preventing suicide, which must be seen as a complex set of decisions or actions precipitated by social-moral, bio-psychic, and physical conditions of lived experiences is that the characterization of suicide as a pathology that must be addressed solely and exclusively by using a biomedical healing model, is grossly inadequate. This idea is captured by the view that a healthy person has harmony among biological, psychological-metaphysical aspects and in harmony with one's social-moral context and relationships with others in a community.

As Menkiti indicates, "the African emphasized the rituals of incorporation and the overarching necessity of learning the social rules by which the community lives, so that what was initially biological given can come to attain social self-hood, i.e., become a person with all the inbuilt excellencies implied by the term" (1984, p. 173). These excellencies indicate one's health and well-being. He argues that one way to understand the fusion of biological, psychological, and social-moral elements in the African view of personhood is that, biology predisposes us to be social-moral beings. In his words, one's "biology intimates a message not of beingness alone, but of beingness together" involving a "mental commonwealth with others" (p. 324). This involves a situation where, "both norm and biology do tend to converge" and "deep biology link[s] up nicely with the direction of movement of the moral order" (p. 324).

Menkiti suggests that our biological nature implies a psychological connection that moves in the direction of a social-moral order in our relationships with others in the community. This moral order undergirds African communalism, conception of personhood, health, and well-being. One's harmonious incorporation into the community, moral order, and internalization of communal values create in the spirit or psyche (*sunsum*) and the person a healthy sense of self, personality, and well-being. As such, proper healthcare and relevant decisions in African traditions take all these aspects of the person into consideration and deviate from pathologizing the individual.

Gyekye's (1984) account of the spiritual (*sunsum*) aspect of the person, which is distinct from, but connected to (interacts with), the physical-biological aspect, suggests that biomedical treatments focus on the physical body and physical health. However, ensuring psychological health in the spiritual (*sunsum*) aspect of the person can be addressed by ensuring one's social-moral health. But the robust health of the person can be addressed by focusing on both aspects and their interactions. This has relevance to the issue of suicide in African because many of those involved in suicide who feel a diminished sense of health and well-being are motivated by and make suicidal decisions based on social-moral communal factors. These include one's social-moral, physical, and psychological conditions, which engender in the spirit (*sunsum*) a diminished sense of self or well-being.

A robust sense of *personhood* and, thus, health and well-being involves one's responsibility to use one's capacities to internalize requisite values that are manifested in one's character and behaviors that promote communal harmonious living, relationships, welfare, solidarity, caring, and mutuality. The community helps people to develop the conditions and values of love, caring, and friendship, which make it possible for individuals to choose rationally a life plan and actions in order to achieve their well-being.

The African conception of personhood as a basis for health and wellbeing, which combines descriptive (metaphysical, physical, and psychological) and normative (social-moral) features, is *relational*, *active,* and *goal-oriented* in two senses. It involves using one's (biological, physical, psychological, and metaphysical) capacities for (1) choosing the *best means* in one's material, social, moral conditions, goods, and lived experiences of a community and (2) achieving the best life plan, self-realization, health, wellbeing, positive sense of self, solidarity, and harmonious relationships with others. The material goods, social-psychological, and normative conditions provided by a community and the requisite obligation requirements do not limit individuals' sense of self-hood, self-realization, health, and autonomy; rather, they expand or enhance them and make them substantive. This makes the idea of personhood *intentional* and *instrumental* in a relevant sense: personhood is constituted of mental states (desires, attitudes, beliefs, and dispositions) and character traits, which are *aimed* at the relevant individual and communal goods or interests that are mutually coextensive and supportive.

The argument for the *relational conception of personhood*, and a contextual and social-moral nature of individual health and well-being, involves the idea that one's biological, physical, metaphysical, and psychological capacities are vacuous if one does not have the material conditions, resources, and meaningful options of goods from which one can choose to achieve one's life plan, self-realization, health, and well-being. Even when one has options and goods, they are meaningless if one does not know their value, in terms of what constitutes a reasonable life plan, self-worth, well-being, and how the relevant options, conditions, and goods can best achieve one's life plan. One's capacities are "primitive tools" and "mere potentialities" to be actualized under certain social-moral context and material conditions in a community. As unguided and uninformed primitive tools and potentialities, human capacities are not functional or effective; they can be misused in harmful ways that are not conducive to one's well-being.

In order for one's capacities be used properly and effectively for one's well-being, they need to be informed, trained, and guided by social-moral norms. Adhering to normative and communal guidance will make it less likely that one will misuse one's capacities to harm oneself and others. Without the communal context, social-moral norms, harmonious human relationships, and solidarity with others, one would lack the proper conditions to develop and actualize one's potential and capacities to achieve health and well-being in order to flourish. These conditions make a robust set of options and goods available and choices substantive and meaningful for one's well-being. The community provides the knowledge and values that enlighten one's choices of what is valuable and meaningful in the relevant context.

The African robust view personhood implies that health and well-being depend on the "internal harmony" within the person, that is, equilibrium and harmonious interaction between the physical and mental aspects, and "external harmony" among the person, others, community, and its norms. As indicated by Gyekye, this philosophical psychological account of the "person" "has had significant pragmatic consequences in Akan [African] communities as evidenced in the applications of actual psycho-physical therapies" (1984, p. 210). These therapies, which are relevant to understanding suicide and its prevention, are predicated on *ethical-based practices*. They involve a "holistic approach" of making an individual wholesome—being a *true person*, which includes the internalization of communal moral norms, attainment, and manifestation of moral excellencies. Unwholesomeness: a distortion in one's moral outlook, sense of psychological self, or lack of social-moral harmony with others in the community could also make someone psychologically and physical unhealthy.

This African conception of personhood requires that in order to have a healthy sense of self psychologically, one must be socially and morally healthy. Hence, in Menkiti's view, "morality ought to be considered as essential to our sense of ourselves as persons" (1984, p. 176) in the sense that internalizing and adhering to communal moral norms create and enhance internal equilibrium within oneself and harmonious relationships and solidarity with others. Thus, "personhood", which involves social-moral and psychological health, is a function of how well one uses one's metaphysical capacities for one's own well-being, which is a function of communal wellbeing and vice versa. The processes for achieving social-moral health are exemplified in *ethical-based practices* that stress contextual social-moral approaches to healthcare and wellness.

Such approaches create the conditions for individuals to optimize their mental and physical well-being, wholesomeness, and social-moral harmony with their community. This raises questions regarding the best approach to individual well-being and optimal health: whether the focus should be solely on biomedical evidence from scientific facts about one's biology and psychology, or on one's robust sense of self in the social-moral context of one's values and lived experiences that contribute to one's robust well-being and health. This has led to a debate about the nature of, and contrast between, *ethical-based practices* and *evidence-based practices*. It has also raised the issue of the theoretical foundation or philosophical justification for any approach to healthcare or an understanding of the overall health, well-being, or wellness of the person. Evidence-based practices involve the pathologizing of patients and the exclusive and sole reliance on scientific evidence as the basis for treatment. However, ethical-based practices involve the call for individualized treatment that considers his social-moral values, beliefs, circumstances, and lived-experiences in order to make the treatment meaningful for the patient.

Ethical-Based Practices and Suicide

This call for an individualized approach to healthcare involves the idea that good healthcare is provided in the context of available resources, options, and treatment methods that make such treatment meaningful and good for the individual based on his or her situation, values, and beliefs. The need to create such a situation for a patient is motivated by ethical considerations and the relevance of one's unique circumstance and available options. This requires practical (means-end) contextual reasoning regarding the best method in any given situation for achieving a desired end of optimal health for the individual. Let me illuminate this debate regarding the best approach and the merits of the *ethical-based approach* by problematizing the nature and inadequacy of the *evidence-based approach* regarding the study of, and the efforts to prevent, suicides. The Western view of the person as defined solely and entirely by bio-psychological features gives credence to the pathologizing of individuals and the accepted truth of *evidence-based approach* in suicidology that the main cause of suicide is depression, or that mental disorder plays a significant role in almost all suicides.

As Isaacson and Rich indicate, the connection between depression and suicide has been found so many times in research that it is now considered "proven" (2003, p. 457). This is often referred to as "the 90% statistic," which is widely accepted in suicidology as a well-established truth based on scientific evidence. The evidential basis for this truth is said to reside in a number of psychological autopsies (PA), usually referred to as "PA studies," where the relevant diagnosis of depression or mental disorder is assigned to the dead person based on interviews of bereaved family members or relatives, a few years after the person's death by suicide. Hjelmeland and Knizek (2017) and Hjelmeland et al. (2012) have raised significant questions about the methodology in "PA studies" that are used as the significant evidence to support the truth of "the 90% statistic." One fundamental basis for questioning the validity of "the 90% statistic" from "PA studies" is that "it is impossible to assign a valid psychiatric diagnosis to someone by interviewing someone else" (Hjelmeland & Knizek, 2017, p. 481).

In reviewing many of the interview questions in "PA studies," Hjelmeland and Knizek (2017) found that many of the questions contain the words, "feel" or "think." They argue that it is difficult, if not impossible for another person (family members, relatives, or friends) to know with any exactitude, the *feeling* or *thinking* of the deceased. In their view, many of the diagnostic questions used in "PA studies" interviews cannot be answered adequately and reliably by proxies, and as such, these diagnoses cannot possibly be accepted as valid. Moreover, the diagnoses from "PA studies" rely on the interviews of some of the closest next-of-kin; but the closest next-of-kin might not have the most intimate information or confidence of the deceased. They also argue that it is quite difficult to separate and distinguish between *sadness* and *depression*, such that they may be conflated by a respondent. Moreover, "PA studies" may involve a kind of self-fulfilling prophecy, in that: "if you hold to a belief that one has to be mentally disordered to die by suicide, I am more likely to see and report symptoms that fit my belief" (Berman, 2006, p. 3).

Hjelmeland and Knizek (2017) argue that evidence indicates that in many quantitative studies, the role of mental disorder or depression in suicide may have been overestimated. They argue that some qualitative studies from Norway and Uganda challenge the widely accepted connection between depression and suicide or that suicide is mainly a consequence of a mental disorder. For instance, they cite studies by Kizza et al. (2012) and Knizek et al. (2011) from Uganda, where mental disorder was mentioned in only one of the 20 suicide cases in their study. Rather, suicide is caused by other social, cultural, psychological, and moral factors, including shame, loss of dignity, social value, hope, a diminished sense of self, and overwhelming burden of social and cultural responsibilities. They also cited Tatz's (2001) study of suicide among Australian Aborigines, which found that "indigenous youth suicide has no basis in 'mental ill-health' (p. vi)" (p. 486).

In general, "Research outside 'the West' has found lower proportions of mental disorder in suicides compared to what is commonly found in 'the West'" (Hjelmeland & Knizek, 2017, p. 484). One of the reasons for the difference between "the West" and places like, China, India, and African countries might be that "researchers outside 'the West' are more open to understand suicide from a nonbiomedical perspective, and more ready to see the contextual issues involved" (Hjelmeland & Knizek, 2017, p. 484). These contextual issues are implicated in *ethical-based practices* in healthcare that suggest the idea that "suicide is a complex and multifactorial phenomenon, and that multidisciplinary approaches are required in suicide prevention" (Hjelmeland & Knizek, 2017, p. 486–487). This is supported by the African view that, because health issues, such as suicide and its prevention, involve a view of personhood, well-being, and mental and social-psychological issues that are shaped by social-moral factors, it makes sense to take these social-moral contextual factors into consideration.

The *ethical-based approach* to suicide involves the examination and understanding of the relevant contextual social, cultural, moral, and theoretical issues. In my view, the African philosophical ideas of communalism, morality, and personhood provide the theoretical foundation and justification for *ethical-based practice* in healthcare and wellness issues, including suicide. These ideas give credence to a method of understanding suicide as a health or wellness issue or phenomenon "characterized by multiplicity, instability, social context, complexity, and historical contingency" (White et al., 2016, p. 4). The African view implicated by *ethical-based practice* takes into consideration the lived experience, context of individuals, and the situation that motivated their suicide—circumstances that must be understood in order to prevent suicide. According to Hjelmeland and Knizek (2016, 2017) and Hjelmeland (2016), the contextualized approach to suicide research, which is motivated by *ethical-based practice*, has contributed more to an adequate understanding of suicide than the traditional, decontextualized quantitative research, which is motivated by the *evidence-based practice*.

The value of questioning the validity of *evidence-based practice* regarding the truth of "the 90% statistic" about suicide is that the *evidence-based practice* could prevent the open, critical, and fair discussions of scientific beliefs and propositions. Such propositions would be accepted as "dogmas," unquestionable, proven, or "the truth" that is supported, supposedly, by the evidence. It might foreclose critical examination of ideas as detailed by Hjelmeland and Knizek (2017) regarding the resistance to their efforts to publish the article that questioned the validity of "the 90% statistic." The central point here is that "the 90% statistic" implies that because suicide is caused mainly by mental disorder or depression, the only way to understand and address suicide is as a bio-psychic pathology that relies exclusively on the biomedical model. According to Hjelmeland and Knizek, “In suicide prevention, it is time to focus more on the complexity that always lies behind a suicide. The biomedical model falls short when it comes to preventing suicide. We need to incorporate the contextual and relational in a life course perspective if we wish to understand the nature of suicide” (2017, p. 489).

This biomedical healthcare approach to suicide is given credence by the Western psycho-physical Cartesian view of the person as an isolated individual that is removed from society and social-moral context. The biomedical model requires that, “The spotlight is thereby directed at the individual, since suicidality is regarded as something that lies inside the individual, while the importance of relationships and contexts receives less attention” (Knizek & Hjelmeland, 2007, cited in p. 489). To reiterate, the essential point regarding this African communal view of personhood and health, as contrasted with the Western view, is that one’s positive and healthy sense of self-hood or identity, which is based on harmonious relationship and solidarity with others in a community, can enhance one’s psychological health, which in turn enhances one’s physical health. Conversely, a disruption in one’s relationship and solidarity with others in a community will adversely affect one psychological and physical health.

The difference between the Western and African conceptions of personhood has implications for how patients make healthcare choices and how such choices ought to be understood and addressed by healthcare providers within healthcare practices. Osuji (2014) illuminates the contrast between the African and Western conceptions of personhood, health, or well-being, in his contrast between their corresponding views of the nature and process of a patient’s decision-making in healthcare. In Osuji’s view, autonomy in African communal cultures involves a situation where a “decision-making process rests on the consensus reached in consultation with the group rather than by the individual patient alone. . . . the Western model . . . places the responsibility for decision-making on the individual patient [alone]” (2014, pp. 2–3). The African view indicates that one’s well-being, health and choices cannot be separated from one’s sociocultural relationship, communal norms, and environment, because one’s sense of self, identity, choices, character, personality, and well-being are tied to one’s communal norms, relationships, and solidarity with others.

The African ideas of wellness, health, self-hood, identity, and choices involve a person being embedded in a caring community, which makes options available, circumscribes them, and guides one to use one’s freewill to make proper choices regarding one’s life plan, health, and well-being. This African idea of a “healthy person” suggests a *relational conception of health*, in that one’s sense of health is a function of one’s harmonious social-moral relationships with others, context, and community. The idea of *ethical-based practice* in healthcare requires communal participation, since the community contributes to individual health and well-being. Let me illustrate how *ethical-based practice* ought to function in addressing suicide in the context of African conception of personhood, morality, and the communal basis for health and well-being. Although it illustrates how African communal cultures *ought to* function, they may not function that way because they have been undermined by colonialism and Western cultures.

A man is contemplating suicide partly because he is distraught about his life for the misfortunes that have befallen him. His only child died in an accident in which he himself was severely injured. He is physically ill, incapacitated, and not able to work to earn a living. His illness and injuries have made him impotent and unable to have children. He *thinks* and *feels* that he is a failure because he is unable to live a life of dignity and provide for his family. He feels a sense of despair, hopelessness, shame, a diminished sense of self, value, control, power, and self-respect, for being a burden on his family, friends, and community. According to Kizza et al. (2012) and Knizek et al. (2011), these factors explain why most men choose suicide in some African cultures and that suicide is not necessarily caused by mental illness or depression.

From his narrow selfish individualistic perspective, he *thinks* that suicide is his "best choice" in this situation and a *means* to avoid shame, loss of dignity, social value, and self-respect because his friends, extended family, and community have now taken on all his responsibilities—consistent with the communal values of caring and solidarity. The community, friends, and family have all rallied to his support; they indicate that they respect him and appreciate that his unfortunate circumstances are neither his fault nor a failure on his part. His friends and family provide moral, social, and psychological counseling for him. Everyone makes efforts to support and uplift him morally, emotionally, and materially—as a form of *ethical-based practice*. He is told that people understand and sympathize with his misfortune and "his felt" inability to provide for his family or contribute to the community.

To dissuade him, they make every effort to make him realize that suicide is unacceptable by African communal norms and that his feelings and thinking are contrary to the communal reality and how he is perceived in the community. He is made to realize that in spite of his misfortunes and lack of financial or material means, he is neither a failure nor perceived as such. He is viewed positively as a generous, kind, and virtuous person and as a valuable and supportive friend and neighbor, who makes significant contributions to the community in various ways; he is a good counselor who has helped many people and always provide emotional and moral support for friends, family, and neighbors. They stress all his virtues, talents, good character traits, and reasons why the community, family, and friends admire, cherish, and value him.

All these communal factors, counseling, and support have the positive effect of giving him a positive sense of self and well-being, and to subsequently inform his decision not to go through with suicide. He has allowed his psychological capacities to be sufficiently informed in order to use them morally and properly in the given communal context to achieve health and well-being. He has come to the realization that his autonomy and choices as a person that are relationally embedded in relationships, a community and its values, are not intrinsically valuable or good to necessarily imply the duty of noninterference and respect by others. He realizes that his choices must depend on the socially and morally acceptable options that the community makes available. According to Osuji's (2014, pp. 1–4) African idea of *relational autonomy in consent* (RAIC), his choice must be "in consensus" with and informed by the communal values of caring, relationships, and solidarity with others. As such, his decision not to go through with suicide makes sense in the African communal context, moral values, obligations, lived experiences, and a relational conception of personhood, health, and well-being.

This decision makes sense because the African ideas of personhood and health indicate that individuals have the capacity to internalize communal values in order to use them properly in the context of and in relation to communal conditions, values, and material goods. Moreover, one is able to make decisions that enhance one's own health and well-being, which are coextensive with the well-being of others, solidarity, and harmonious relationships. As such, a person cannot see his conception of the good, health, well-being, life, and the basis for his decision to take his life, as something that is independent of the social-moral context. The African conception of personhood and communal mixed-deontological ethics imply that one's choice of suicide lacks goodwill and shirks one's obligations to oneself, one's family, friends, and community. Such obligations also require that one should not focus solely on one's self-centered thinking but on one's relationships, obligations to one's family, friends, and the general welfare of a community. Such obligations require one to appreciate the bad consequences that suicide would bring to one's family, friends, and community, in terms of the shame, stigma, and social disharmony it will cause, and the loss of one's positive contributions.

The adequacy of this man's decision not to take his life must be viewed from an *internal point of view* regarding the communal context and relationships for those who accept the relevant social-moral norms and use them as a guide for their conduct. It also gives credence to the idea that suicide is not necessarily caused by mental illness or depression, that we should not address it by relying solely on the biomedical model, and that it could be prevented by communal support, "counseling" and intervention, where everyone has a part to play.

This example implies that it is when one sees oneself, capacities, health, well-being, and choices *relationally* as, an organic part of a community or relationships with others that one can see oneself and be considered as a *true* and robustly healthy *person*. This African communal approach to suicide and wellness is exemplified by the International Association for Suicide Prevention (IASP) slogan for World Suicide Prevention Day 2005, which is "Prevention of suicide is everybody's business" (www.iasp.info). Thus, Hjelmeland and Knizek (2017) indicate "Everyone can contribute to suicide prevention. This is an important message to get across to the public, and the constant reiteration of 'the 90% statistic' by influential professionals hinders this communication" (p. 489).

Conclusion

I have argued that one's biological and psychological features alone cannot adequately capture a robust sense of personhood, self-hood, health, or well-being. As such, in healthcare practice, one cannot adequately address one's health and wellbeing by addressing only the biological nature of a person. Although our biological and psychological nature will shape who we are and how we feel, it cannot robustly define our health and self-hood. In addition to one's biological and psychological nature, one's sense of self-hood, well-being, and healthy must depend on external contextual factors of the material conditions, goods, and values in a community that allow one's capacities to be used meaningfully in a particular context to achieve self-actualization, well-being, and wellness. One's health and self-hood depend on how one uses one's biological and psychological nature in the social-moral context of a community to make the proper choices and act, in order to achieve well-being and personhood. On the issue of one's health, self-worth, and well-being, or lack thereof, that could lead to suicide, one's community, value systems, lived experiences, and relationships with others have a significant role to play.

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Chapter 12
Perspectives on Meaning-Making Among Disenfranchised Minorities as Illustrated by a Group of Gender and Sexual Diverse Individuals in Uganda

Kibuka-Musoke Elizabeth and Hama-Owamparo Severus

Introduction

> In this way, life is like a dance. We do not dance to get to the end of the dance,
> or to get to some particular point in the dance.
> Rather, we dance for the sake of dancing. Dancing is its own reward.
> Unknown

Lake Bunyonyi is the third deepest lake in the world situated at the base of steep, sleepy terraced hills where the indigenous Bakiga people of Uganda live their lives under a joyful worldview they call 'Okushemererwa', which loosely translated would mean 'the right to a life of continuous happiness' or 'Sheer happiness in/of existence'. Indeed, there is a 'live and let live' artlessness and candour that is frankly contagious.

The Bakiga are like the rest of us, they hold up axioms, no doubt much in the same fashion as other societies do when they rally around equivocal values such as "freedom", 'peace' and 'equality', but live much of their lives according to different strokes. What would meaning-making look like to different peoples? Would they all make meaning the same way? Would worlds that are so far removed from each other have the same existential meaning-making apparatus, structures, needs and applications? Or would presumed similarities (spirituality, religion) or power inequalities (who 'owns' the dialogue and access to resources), skewer our understanding of the dynamics of meaning-making? Are others' meaning-making structures pertinent to ours or adjacent to them? Is there really a universal theory of meaning-making, or is it applied selectively, based on certain rules? Would constructs be qualitatively different and therefore lead to a redefinition of the theories of meaning-making in

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its present form, or would they validate it further in terms of its relevance to all human meaning-making structures?

We sat on a precipitous hillside watching Lake Bunyonyi observe us from below in its silent stillness. The lake's impenetrable darkness reflected our own, as yet unformed, speculations.

Our thoughts led us to ask if meaning-making structures would deviate in any significant way under the experience of disenfranchisement, much in the same way personality development may deviate into personality disorder as a direct experience of trauma? Do dominant worldviews or narratives—such as religion, culture, or power—invade or sweep away alternative meaning-making attempts, even with the help of the members of the minority groups themselves?

In an attempt to answer some of these questions, we asked for consent of a small group of people, members of a disenfranchised community going through a therapeutic process, to make use of some of their statements to trace any effects of loss of personal agency on meaning-making structures. As much as we had had some successes working with lesbian gay, bisexual trans* and queer patients, there were so many questions left unanswered and gaps in knowledge that our simple sample size just could not answer. Our intervention and consequent perspectives were centred among Gender and Sexual Diverse (GSD) persons in the central region as a subsection of disenfranchised minorities but might be useful also for larger populations.

Gender, Sexuality and Identity

According to the American Psychiatric Association (2020), gender has two components:

1. Gender identity: A person's basic internal sense of being a man, woman, and/or another gender (e.g. gender queer, gender fluid).
2. Gender expression: Conveyed through appearance (e.g. clothing, make up, physical features), behaviours and personality styles. These means of expression are often culturally defined as masculine or feminine. The ways in which people express their gender identity are both particular to each individual and variable across cultures.

Such a definition implies that gender identity is separate from identity and not a part of it. It further argues that the yardstick for gender is man and woman. Anything beyond this scope is 'other'. The second component associated with gender is not only reductionist, in that it equates diverse human expression to gender, but also states that gender expression commutes between a dichotomy of culturally determined aspects of masculinity and femininity that can be quantified through a culturally gendered lens, which determines how physical appearance, clothing and makeup contribute to this definition. Finally, this definition ignores the role of sex in determining gender. If we were to adopt this definition of gender, what we would be insinuating is that how someone feels, behaves and what they wear is their gender. This is not a stance that this chapter can agree to.

For purposes of this chapter, we will redefine the terms gender, gender diversity and sexuality. Gender: one's internal relationship to own sexed body and how that translates into expression, self-perception and identity. Another argument we would like to put forward is that gender does not have to be an expression of either masculinity or femininity and the culturally associated factors thereof. These aspects can exist in the realm of both and beyond. Gender diversity explores the vast expressions of gender. Gender diversity as a term is descriptive and asserts that gender is individual, innate and non-restrictive so much so that the need for an addition of diversity after the term gender can be argued as unnecessary. Sexuality, on the other hand, involves ones sexual or non-sexual attraction and preference to different individuals regardless of sex and gender. Sexuality can be heterosexual, homosexual, bisexual, fluid or asexual.

Gender and sexuality are a part of one's identity that forms over the course of one's life and cannot be solely determined by self (Mascolo, 2019); just as any other component is, internal or environmental, conscious or unconscious that shapes who individuals are and become over the course of their developmental cycle. When we alienate these facets insisting that they are the being in totality, we reduce the humans and their experience to no more than the hair on the head or lack of, or the colour of skin or illnesses that one struggles with. In doing this, we perpetuate harmful stereotypes and biases that we associate with these aspects that are no doubt, culturally bound and further away from the truth. This hinders our ability to sense with our sensibilities the nature of things and our ability to sit steady with the unknown or different, without immediately diluting or averting from it.

Locus of Control

The notion that little in life is under one's control is a worldview quite different from the Euro-American belief that much in life can be modified through personal will or intervention. It is important for clinicians to consider that the ecology of lower socioeconomic status can disempower individuals and limit their hopeful outlook. The belief in an external locus of control should not be taken as a deficit but rather as a realistic and philosophical form of coping by trying to accept circumstances that may be beyond one's control. This in turn tips the self-fulfilling prophecy scale to the degree of internalization of these circumstances.

This may mean an attitude of learning to live with a problem rather than insisting on resolution, a notion that may be foreign to practitioners who have internalized an optimistic positive action outlook (Falicov, 2016). The challenges involved in working among vulnerable populations include appropriate and effective interventions (Natale & Moxley, 2009) that have a holistic understanding of the ecology and how it affects health outcomes.

Contextualisation of Gender and Sexual Diverse Persons

Uganda and Post-Colonial Africa has a gruesome history of unethical methods being used to address issues of sexuality, gender diversity and expression. Cases of ‘corrective therapy, corrective and deserved rape’, as well as religious-informed ‘cures’ to ‘treat’ GSD individuals are not unheard of. The one thing all these ‘treatments’ have in common is the promise of a ‘cure’ by attempting to make such person heterosexual, or conform to a strict dichotomy of gendered stereotypes of expression. There is a plethora of research that confirms the determinants and counterproductivity, regression and pervasiveness of such efforts as they cause more distress and do more harm to the individual in question (Outright Action International, 2019). When ‘treatment’ produces a negative outcome, it does not matter if it is the only known treatment, something must be changed. Further still, ‘treatment’ cannot be called treatment if there is no illness/disorder in question. Such methods are not only highly unethical but are unempirical and very dangerous.

Many Ugandans believe that Ugandan law does not protect GSD persons. This is based on a gross misconception and is mother to widespread hostility. Such attitudes are based on the prohibition of same-sex sexuality in the Ugandan Constitution, as well as the criminalisation of ‘carnal knowledge against the order of nature’ in Uganda’s Penal Code Act. Such narrow interpretations of the law fuel bias and are very dangerous as they deny GSD people of legal protections that are available to them as a right, on the same grounds as other people (Human Rights Awareness and Promotion Forum, 2019a, b). This is constraining and detrimental to the mental health and well-being of these minorities and any developing state broadly (Radcliff, 2016). GSD persons are therefore tasked with surviving within a legal double bind.

Article 21 of the Ugandan Constitution provides for equal treatment before the law in all spheres of life, i.e. political, economic, social and cultural spheres of life and also prohibits discrimination against people on the basis of sex, race, colour, ethnic origin, tribe, birth, creed, religion, social or economic standing, political opinion or disability and such persons also have the right to privacy as stated by Article 27 which provides for protection from interference with the privacy of any person’s home, correspondence, communication or other property. Despite these provisions, the same laws contradictorily enforce inhumane restrictions to this particular group of people, in direct violation of their right to equal treatment and non-discrimination. Article 31A, introduced in the 2005 amendment of the Ugandan constitution, prohibits same-sex marriages, thereby inhibiting the full exercise of rights and freedoms of GSD persons. Further still, Uganda’s Penal Code section 145 bans ‘sodomy’, stating that:

> Anyone who has carnal knowledge of any person against the order of nature . . . or permits a male person to have carnal knowledge of him or her against the order of ‘nature’ commits a crime punishable on conviction by life in prison.

In addition, the Penal Code prohibits what it calls ‘indecent practices’ by any person. It is important to note that Article 31A and Section 145 of Uganda’s Penal Code do not criminalize homosexuality as sexuality and neither do they criminalize homosexuals as a group of people; they prohibit ambiguous sexuality acts of 'same-sex' conduct (Hama-Owamparo, 2018). None of these laws even begin to address the gradation and intricacies of gender that are often engulfed under or conflated with sexuality. GSD persons are negatively perceived, and this justifies hostility and abusive behaviour by the rest of society towards GSD persons thereby depriving them of their right to liberty and assembly. Fear, animosity, preconceived bias and stereotyping have been instrumental in laying the ground for the numerous human rights violations and various forms of violence—from domestic to state sanctioned injustices—faced by these individuals.

The subjection of suspected GSD individuals to anal examinations, non-consensual HIV tests, defamation before the media as 'homosexuals' and prosecution in courts of law for being who they are is profoundly brutal (Human Rights Awareness and Promotion Forum 2019a, b). Why the Constitution and population of Uganda are more concerned with degrading the freedoms of this particular adult population, in the most intimate and private of settings, than they are with protecting such persons from all forms of violence and inhumane treatment, is unconscionable! Perhaps similar psychological mechanisms lie behind xenophobia in a continent that is still largely recovering from the aftermath of colonialism.

Minority Stress and Syndemic Vulnerability

The concept of minority stress emerged out of social and psychological theory to describe a relationship between minority and dominant values and its effect on the social environment experienced by minority group members (Meyer, 1995; Mirowsky & Ross, 1989; Pearlin, 1989). Minority stress theory contends that sexual minority health disparities can be largely explained by stressors induced by a hostile, homophobic culture, which often results in a lifetime of harassment, mistreatment, discrimination and victimization (Meyer, 2003). This may ultimately impact access to, and quality of, care. Underlying the concept of minority stress are the following assumptions: that stressors are not experienced by non-stigmatized populations; that they are chronic and that they are socially based, as in, related to social and cultural mechanisms as well as social processes, structures and institutions (Meyer, 2003). While this theory has been applied to other populations, including women, immigrants, the impoverished and racial/ethnic minorities, there is still much room for additional investigation among sexual minority populations, as they do not have as rich a history in sociological investigation (Meyer et al., 2008). A strong correlation may be drawn between (a) minority stress theory, which underscores stress processes (experience of prejudice, expectations of rejection, internalized homophobia) and ameliorative coping processes (Meyer, 2003); and (b) a greater likelihood for psychological distress and physical health problems among gay and bisexual men and other sexual minority populations.

Minority stress can appear in several different forms. While much of the literature has focused on major discriminatory events, more recent work has begun to examine microaggressions that occur in daily life. Microaggressions are generally characterized as brief, daily assaults on minority individuals, which can be social or environmental, verbal or nonverbal, as well as intentional or unintentional (Balsam et al., 2011). Considering that theory emphasizes the cumulative nature of minority stress (Meyer, 2010), individuals experiencing microaggressions because of their racial and sexual minority identities may be especially vulnerable to poor mental and physical health outcomes. The existing theory on intersectionality and research on LGBT-POC (people of colour) suggest that these individuals may experience unique stressors associated with their dual minority status, including simultaneously being subjected to multiple forms of microaggressions. In politically hostile environments, similar mechanisms are at play. What this could result in is black self-hate, internalized homophobia and compulsory heterosexuality—the merging of self-hatred and shame into one's belief system is also a source of stress (Balsam et al., 2011). The culmination of all the above factors with the effort at concealment of sexual orientation or, conversely, the stress of 'coming out' into environments that are fraught with unacceptance, expose one to the risk of exclusion from the last bastion of support—the family. Research studies conducted in developed countries have found that higher levels of internalized homophobia were associated with higher levels of mental health problems, i.e. depression and anxiety (Russell et al., 2006).

The minority stress theory also feeds into syndemic studies, rooted in anthropology, that further highlights synergistic, often deleterious, interactions among comorbid health conditions, especially under circumstances of structural and political adversity. GSD persons and other disenfranchised minorities exist in positions subject to minority stress and vulnerability that are normalized in their environments and yet, health and human rights research draw on international law to argue that all people deserve access not only to health care but also to the underlying determinants of good health (Willen et al., 2017), an element severely lacking within-state recourse. The solution to these imbalances and inequities as suggested by Willen and colleagues would include:

1. Mapping the effect of social, political and structural determinants on health.
2. Identifying opportunities for upstream intervention.
3. Working collaboratively to tackle the structures, institutions and processes that cause and exacerbate health inequities.

At present, globally, laws and lip service have been enacted in many countries to protect the rights of women and black people. But many other countries have resisted extending human rights to protect lesbian, gay, bisexual, trans*, intersex and queer persons, defending their stance as one of resistance against western mores or religious transgression (*see* also Tamale, 2014). This has no doubt that it had a significant effect on the physical and mental health of this community, not to mention the effect it has had on incentivization and acceleration of social injustice against it. We therefore assume that:

1. Powerlessness over the making of personal meaning leads to psychological distress.

2. To help overcome that distress, there is a need on the part of mental health professionals to understand how minority group members process and structure meaning-making and how that affects their functioning, in order to improve therapeutic interventions.
3. Therapeutic interventions must be based on an encompassing understanding of minority circumstances as opposed to strictly applying evidence-based models to different groups minus this understanding.

Powerlessness Over Personal Meaning Leads to Psychological Distress

One of the goals of writing this chapter is to raise the level of attention given to the implicit bias that may conceal the underlying structures of meaning-making differences between the 'haves and have nots'. The juxtaposition against a normative value at greater and greater distance from normative meaning, strips one of their right to define their existential meaning.

Meaning-making is a function of power, influence and privilege vested in majority rule. This defines the meaning-making of the rest of the world and provides the lens through which all other sense-making is understood and judged. Cultural identities are influenced by the constructs supplied by the dominant discourses, and cultural location is described only for minority groups and thus the implication here is that culture and society influence only marginalized groups while dominant groups are regarded, implicitly, as the standard norm (Falicov, 2016).

Take, for instance, the three levels of distance of female/male, black/white, queer/straight. What would a queer, black female and her existential meaning look like after crossing so many lines of 'normativity'? Take the first level of normative—male/female—which Betty Friedan in her book *The Feminine Mystique* describes how women suffered under a pervasive system of delusions and false values under which they were urged to find personal fulfilment, even identity, vicariously through the husbands and children to whom they were expected cheerfully to devote their lives. This restricted role of wife–mother led almost inevitably to a sense of unreality or general spiritual malaise in the absence of genuine, creative, self-defining work. (Friedan, 1963, pp. 27–29).

When we include a second level of removal from normative—the white/black polarity: the message seems clear: Black lives do not matter equally to White lives. Systemic racism with the barrage of racial microaggressions remind Blacks daily of their unimportance and reinforce White privilege (Hoffman et al., 2016). It is probably fair to say that this is, to some degree, the experience of all people who are non-white, but the writers of this chapter are black Africans and we are restricting ourselves to the black experience. The black experience is wider than the Black American experience, but both share the internal oppressions that are the results of years of slavery, colonialism and racism. Both share the results of that oppression, often described as internalized self-hatred that informs the pervasive belief that black people are inferior. With South Africa in mind, Magezi (2020) puts it this way:

> Although Baldwin's (1979:58) notion of black self-hatred is perceived from an African–American context, it does play a role in assisting us to see how deeply entrenched self-hatred has become in the lives of black people in Africa... p. 1

Magezi further postulates that:

> . . .most Africans find themselves in a helpless psychosocial 'space' which clouds them and pays undue attention to wrong things instead of self-advancement and playing part in taking South Africa forward, among other important things... p. 2

The third level of normative falls along the straight/queer dimension—having passed through the two former prisms—and intensifies the force of the dominant dialogue and its attendant minority stress. Here, as in all the above levels of removal from the normative, minority stressors, internalized homophobia and self-hatred are key to psychological distress and disconnect. Power, privilege and implicit bias weave around each other to maintain the air of hostility against the non-normative, underprivileged and disenfranchised, further exasperating the determinants of a decline in mental health. Comprehension of these facets and their influence on experiences is at the helm of determining the success rates of psychological interventions as elucidated upon in the next section.

The Role of Mental Health Professionals and Theoretical Interventions for Minority Groups

The contention here is that powerless, minority groups share certain features of meaning-making structures and functions that differ qualitatively from those of majority groups. We wanted to highlight this argument, with eight GSD community members who agreed to participate in a group therapy. At the heart of our intervention was the need to create a safe and respectful space for participants who have lost their trust in the health-care services available to them due to prior negative experience from reluctant health-care providers. It is within this context that we attempted to address the issues of functional meaning-making on mental health. By functional meaning-making, we mean one's ability to assimilate, i.e. receive new information, accommodate that new information and integrate it into a new experience of meaning. We believe that this is similar to what Park and Edmondson (2012) refer to as the universal human need for meaning as a drive to understand one's experience and to feel that one's life has significance and purpose (integration).

During the intervention, we discovered that safety and respect was experienced by all the participants. They remained sceptical about the health-care system in general but responded well to this group therapy intervention. Functional meaning-making was addressed indirectly. However, after the intervention, all participants experienced improved understanding and optimism of lived experience. They also reported improved well-being, psychosocial adjustment, connection and belonging. By bringing people together in this therapeutic intervention, they were able to form trustful connections amidst harsh socio-political environments. This suggests that group intervention is not only therapeutic in nature but also allowed for the voicing of common grievances as expressed by one of the participants:

> Pretty amazing, I have gotten so much done and my people skills are getting better. I am currently working on how best to communicate during times of conflict or high energy spaces and it feels great.

Immediately after the intervention, all participants noted an overall improvement in their mental health and overall well-being, in line with a host of more specific meaning-related needs that correspond to those identified by Park and Edmondson (2012): agency, control certainty and identity, social validation values and the need to cope with trauma and awareness of our own mortality: I am more affirmative about how my mental health is affected and more aware of what losing the will power to control the environment around me can do to my mental health.

Although some symptoms were still present post-intervention, they were significantly less severe. Participants also reported that they were still actively using tools learnt during the intervention, 6 months later, suggesting enduring benefits and a reduction of dysfunction. The results of our intervention indicated a decrease in depression and in symptoms of disturbance, as well as an increase in self-efficacy and identity.

There was evidence to support changes to functional meaning-making and its effects lasted for at least 6 months beyond intervention, suggesting its integration and accommodation into everyday living. This is what was attempted with our intervention and something that we pose is essential to the livelihood of other disenfranchised minorities despite the economic, structural, cultural, social-political and geographic inequities. If the results of our intervention are anything to go by, then we might yet reimage and recreate a state of psychological homeostasis, dignity and identity even amidst uncertainty, injustice and cruelty. Mental health professionals have a lot of work to do in expanding our knowledge and praxis. We have already begun, and it is too late to halt.

Our journey took us to heights and lows as members of groups that are often measured against a sliding scale of variables and measures culled from populations for which these questions are relevant. We discussed its applicability, its transcendency and even its significance for us as ethnic African researchers, of female or trans* experiences, among other factors. In other words, we were soul-searching our intentions on the one hand and investigating whether meaning-making is indeed focused on the same mechanisms, the same functions and the same conditions as meaning-making elsewhere, or is it qualitatively different. The most important discovery for us was that meaning-making is a state (homeostasis) and an imbalance as well as a drive to understand one's experience within their immediate context and to feel that one's life has significance and purpose (Park & Edmondson, 2012).

Concluding Remarks

As practitioners with two very different experiences across gender and sexual orientation lines, we reflected upon how the results of our therapeutic intervention would translate to other minority communities and populations so as to confirm that meaning-making is, indeed, a universal function, a universal compulsion that has roots and structures that are recognizable even when different in expression and circumstances. We posed ourselves some questions at the beginning of this chapter that guided our thinking. We now refer back to them. Have we been able to answer them?

- What would meaning-making look like to different peoples? We believe that it will look different to different people.
- Would they all make meaning the same way? We did not answer this question, but we believe it is relevant to further research.
- Would worlds that are so far removed from each other have the same existential meaning-making apparatus, structures, needs and applications? And would presumed similarities (spirituality, religion) or power inequalities (who 'owns' the dialogue and access to resources), skewer our understanding of the dynamics of meaning-making? Our position is that the further you are from the central majority normative, the less likely you are to shift the narrative.

Furthermore, we were unable to answer certain questions that we feel are pertinent to our subject matter and worthy of further investigation. These are:

- Are others' meaning-making structures pertinent to ours or adjacent to them?
- Is there really a universal theory of meaning-making, or is it applied selectively, based on certain rules?
- Would constructs be qualitatively different and therefore lead to a redefinition of the theory of meaning-making in its present form, or would they validate it further in terms of its relevance to all human meaning-making structures?

In conclusion, we posit that meaning-making is a function of power, influence and privilege vested in majority rule. This defines the meaning-making of the rest of the world and provides the lens through which all other sense-making is understood and judged. Cultural identities are influenced by the constructs supplied by the dominant discourses, and cultural location is described only for minority groups and thus the implication here is that culture and society influence only marginalized groups while dominant groups are regarded, implicitly, as the standard norm (Falicov, 2016). Disenfranchised minorities exist in a space of limited rights and freedoms which in turn stretches the extent to which an external locus of control takes precedent. This constrains one's capability to shift inward, hindering functional meaning-making. Shifting that perspective without negating the effects of the external tensions on one's internal mechanisms and understanding thereof is integral to positive outcomes.

Appendix: Terms of Definitions Used

Disenfranchised Minorities:	Culturally, ethnically, gendered, sexual or racially distinct groups that coexist with but are subordinate to a more dominant group; as such are deprived of the tenets of basic humanity. This is descriptive in nature and not a label in itself.
GSD:	Gender and sexual diverse persons. In this chapter, it is used interchangeably with lesbian, gay, bisexual, queer, non-binary, transsexual and transgender persons.
Identity:	Identity encompasses the memories, experiences, relationships and values that create one's sense of self. This amalgamation creates a steady sense of who one is over time, even as new facets are developed and incorporated into one's identity.
Power:	In psychological science, power is defined as one's capacity to alter another person's condition or state of mind by providing or withholding resources—such as food, money, knowledge and affection—or administering punishments, such as physical harm, job termination, or social ostracism. This definition de-emphasizes how a person actually acts and instead stresses the individual's capacity to affect others. (Keltner, 2007)
Sex:	A biological construct defined on an anatomical, hormonal or genetic basis.
Sexed bodies:	Refers physical structure of an organism in relation to its sex characteristics. Gendered ascriptions, stereotypes, expectations and roles are then assumed and attached to sexed bodies.

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Chapter 13
From Local Evidence to Global Science and Onward to Local Practice in a Post-Pandemic World: The Journey of Family Intervention Programs in India

Nandita Chaudhary

Introduction

This chapter will focus on two important intersections in the transfer of knowledge from science to practice taking the specific instance of family interventions related to early childhood care and education in India. The first is the transfer of 'local evidence' as global policy and the second is the application of global policy to local communities. These transfers have many warps and cracks which prevent good intentions from reaching imagined objectives, leading to wastage in resources and unintended outcomes. During the recent crisis, international aid agencies in India withdrew into the background, with the possible repatriation of international employees to safer places from where they have travelled as employees. The frontline workers were all local government health, welfare and education workers who placed their lives on the line for protecting the massive population. International aid agencies, it is evident from the recent events, are no longer viable in this new world order. They depend on twentieth century international relations for their ideology and ethics, drawing from an older, post-war and post-colonial neo-liberalism. In present times, welfare work needs to focus more on principles of social justice and equality than on ideas of deficit and disadvantage that draw inspiration from the 'culture of poverty' approach in the social sciences.

There is an urgent need to conduct an audit of international interventions to prevent global wastage of resources and failures to reach objectives. Furthermore, there are several significant social interventions that have emerged from local agencies that have reached significant accomplishments that need attention, and even nationalist agendas have become viewed as hegemonic (Gupta & Padel,

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2021). In the case of international NGOs, the disproportionate expenditures on salary and infrastructure in comparison with local populations and their recent withdrawal from active interventions is a case in point, but that is a matter for another discussion. Here, I will examine the possible and necessary shift from 'evidence-based' interventions to 'ethics-based' interventions for assisting families and children living in difficult circumstances because of the intended and unintended consequences that may happen on account of interfering with the delicate balance between families and their balance with the ecological, social, economic and cultural setting in which they live. Simply making changes in family practices in the name of evidence-based research, without corresponding changes in circumstances, can interfere with this balance and lead to greater disadvantage.

The Context of Poverty

Poverty is a condition that is defined negatively, by an absence of something. A person who does not have sufficient resources to fulfil his or her needs is defined as being poor. In the absolute sense, poverty is defined as complete lack of means to provide for one's basic needs like food, clothes and a home. Given the difficulty of living with poverty, it is seen as a basic human responsibility to make efforts to ensure that everyone in the world has access to basic resources outlined in the sustainable development goals of the UN[1] as a primary objective, to eradicate poverty in all its forms, everywhere. The task has been harder to achieve than was imagined.

To better understand the dynamics of international aid and family interventions, it is important to first address what we know (and also what we do not) about poverty contexts, since family interventions by global, national and local agencies are mostly targeted towards aid for families living in poverty contexts. From the perspective of an affluent nation and its citizens, the experience of poverty is judged from a distance, mediated and also, grossly distorted by media and public attention. This is not to discount the difficulty of living with poverty, but the label instantly invokes distant images of large populations of dark-skinned people, where hunger, degradation and destitution conjure up associated images of violence and chaos. The links between poverty and violence are automatic. The contrast between a svelte celebrity who has maintained her figure by careful control on food intake as ambassadors of humanitarian aid alongside a child, too frail to remove the fly off her eye will go down in our memories as dramatic symbols of global disparity. As Younger writes in her heartfelt story:

> Some say, poverty exists, so shouldn't we expose it? It's true, poverty does exist and famine exists and destitution exists (the reasons why I do what I do) and we need to make people aware of that. People should not be blind to the problems of this world and the plight of the

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[1] United Nations Sustainable Development—17 Goals to Transform Our World.

> billions of people living without their basic needs met, in vulnerability and other unacceptable situations. However, I'd argue that these images are not helping the 'West' to better understand poverty and how to address it. *Rather they are creating false impressions that poverty will be solved by 'charity'*, by sending a few books, a new dress, and a bit of money. That's wrong. Poverty is a complex situation of systemic problems, structures of inequality, inadequate social services on top of individual circumstances. Donating a bunch of books or second-hand clothes is not the way to solve the difficult structures and systems that result in global inequality, vulnerability and poverty (Emphasis mine. Hird-Younger, 2014).

Among wealthier countries, there is little attention to local poverty even though it may be much closer to home than people imagine. In his path-breaking study of the housing crisis in the US, Desmond (2016) does a thorough analysis of the race-based cycle of destitution and homelessness that is perpetuated by local and federal housing policies. Thus, there are poor people in wealthy nations that are largely invisible in the global coverage of poverty. From stories we read about economic status, being poor is assumed to be an outcome of personal disposition like laziness, bad habits, drug dependence and general criminality. These assumptions are largely untested, whereas systemic factors like geographical location, resource availability, local production, land quality, water and housing are likely to have a direct linkage with poor access and availability. Despite this, the public remains firmly wedded to the discourse about the poor being lazy and worthless, thereby remaining within the so-called 'cycle of poverty' (Lewis, 1998). It is far easier for people to imagine that the poor are this because of their poor attitudes, beliefs, values and practices than to accept that we all have a serious role to play in making people poor in the first place and keeping them in a state of poverty subsequently. In the Global South, people are more likely to be poor because they were born in a poor family.

The Meaning of Being Poor

The Italian philosopher Agamben (1998) argued that conflating the concept of life as a biological fact on the one hand and as a lived experience on the other has resulted in obscuring political and biological aspects of people. Life is reduced to a 'bareness' when only biopolitics is considered and individuals become seen only as bodies without power. Scanning the discourse on poverty makes this 'bareness' even more obvious as the 'poor' are perceived as bereft of everything other than their condition of not having enough to sustain their own basic needs. The little that they may have by the fact of being human is also silenced by such an approach. There is a need to acknowledge that the poor are human, individuals, communities, families, with aspirations, strivings, vitality, survival, love and longing, like everyone else. Conversations about poverty severely lack this perspective (Singh, 2015), thereby denying people's right to their dignity and self-respect. Singh's ethnographic work was undertaken in an area characterized by what was referred to as 'unthinkable poverty' in the press. After years of sustained contact, Singh reaches the conclusion that the quality of their lives is defined by precisely those aspects that cannot be measured.

Why have we failed to allow the poor to live with the few things that they have? Why have they been only defined by what they do not have? This feels like a double injustice. Attributes like wealth, affluence, education and literacy do not make us human, life does. But these are the very elements ignored in discussions of poverty, as if humanitarian aid is justifiable only when the poor are stripped of everything they own, including self-respect and dignity. People living with poverty are in the situation on account of a variety of conditions. Their lack of resources could be the consequence of location, ecological conditions, geographical remoteness, social pressure or personal choice. Yet, when poverty is studied, the reasons are invariably related to personal disposition. At this point, it is important to return the idea of a 'culture of poverty' mentioned earlier. Oscar Lewis (1998) stated that the values of people who live with poverty play a critical role in perpetuating their situation, a cyclical phenomenon where the poor raise offspring with values that continue to keep them in poverty. "The subculture [of the poor] develops mechanisms that tend to perpetuate it, especially because of what happens to the worldview, aspirations, and character of the children who grow up in it" (Lewis, 1969, p. 199).

Although the culture of poverty approach was subsequently used in policy documents of several countries, it has also been strongly criticized as having a fundamentally political agenda, one that would attribute the condition of people's lives to the people themselves, rather than focussing on policy (Stack, 1974), and the theory was found to be fatalistic and inaccurate. The idea of COP (Culture of Poverty), Stack argued, better serves the interests of the rich than explaining the situation of the poor. With reference to American society she writes,

> The ideas (COP) matter most to political and scientific groups attempting to rationalize why some Americans have failed to make it in American society.…They (People) want to believe that raising the income of the poor would not change their life styles or values, but merely funnel greater sums of money into bottomless, self-destructing pits. This fatalistic view has wide acceptance among scholars, welfare planners, and the voting public. Indeed, even at the most prestigious university, the country's theories alleging racial inferiority have become increasingly prevalent (Stack, 1974, p. 6).

The evidence on which the categorization of poverty is based on measures income, resources, education, occupation, residence or calorie intake. Yet a lot can be missed in such an approach, and people's lives become boxed into minimal categories that are likely to be misrepresented and misused. When qualitative evidence is taken into account, from ethnographies, conversations, field observations, for instance, one hopes to discover the rules of routine behaviour, and the observer himself must attempt to learn how to move appropriately inside the private world of the people being observed. The researcher must take the time, patience and practice, making efforts to minimize the distance between the model others who are used to explain standards and social order. Attempts will fail, but this prodding hopefully will bring the observer to an intimate point of contact in the study whereby he becomes both an actor and a subject whose learned definitions can themselves be analyzed (Stack, 1974, p xiv-xv).

The Reasons for Poverty: Historic, Social or Psychological?

Poverty is a topic that generates dramatic reactions. Undeniably, living with less than is necessary for the fulfilment of basic needs is something that needs intervention from others, whether it is extended kin, community, state or global agencies. The remedies suggested balance on the assumed causes and attributions. For instance, socialist tradition views poverty as a problem of distribution, capitalist economies and neo-liberal policies make attributions to personal traits and choices, both for the explanation of success and poverty.

Absolute or extreme poverty is identified as being consistent across time and culture and is defined as the condition characterized by severe deprivation of needs like food, water, sanitation, healthcare, shelter, education and information. Relative poverty looks at poverty from a social angle, defined contextually. The poverty line is defined as a measure of a level below which people can be contextually defined as poor. Apart from income, other indicators like life expectancy, child mortality and calorie consumption have also been used to define poverty conditions. The term ‘secondary poverty’ is defined as a condition of deprivation brought on by personal expenditures like gambling or alcohol consumption. Attribution of poverty to laziness is not new. However, in the social sciences, the linkage emerged from research done in the US, a conclusion that was criticized by Alston (2018) by the claim that such depictions of poverty were unethical, inaccurate and unjust, where the rich are characterized as industrious and hardworking and the poor as lazy. ‘The poor are overwhelmingly those born into poverty, or those thrust there by circumstances largely beyond their control, such as physical or mental disabilities, divorce, family breakdown, illness, old age, unliveable wages or discrimination in the job market’ (Alston, 2018, p. 6). Regarding the way in which the poor are understood, Alston argues that stereotypes and caricatured narratives are usually not far beneath the surface, and criminalization of the poor is a common outcome. Alston’s observations can also be applied to international politics of poverty. These stereotypes and narratives prevail around the world, leaving little room for negotiating structural poverty, community-level factors and regional differences. The poor, as a result, are unfortunately left standing with an additional burden of being assumed to be worthless and lazy. A closer look into the lives of the poor sheds light on the fact that nothing can be farther from the truth, despite the fact that these positions are claimed to arise from (a small range of) research studies repeated and re-used whenever required. Whether this is done to put interventions in place, justify skewed policies or lighten our guilt is a matter that needs to be discussed.

In the case of poverty in developing countries, The Global South or low- and middle-income countries, as they have been variously labelled, it is a serious injustice to imagine that people are poor because they are lazy. People living with poverty are born in a specific region, in a specific community, and not on account of their temperamental characteristics. Within the community, the relative position of individuals or their families may be affected by such factors and the fact that some people who can be labelled as poor because of poor choices they make cannot justify the application of that principle to everyone. Yet, it is commonplace and also impacts the ways in which humanitarian aid and intervention programmes are run.

About attributions, Davies writes that:

> [T]reating a complex system as though it is simple is a dangerous game; heuristics can misrepresent the world in consequential ways. Indeed, the unpredictability of the course of our lives is partly due to rich causal complexity of the social world, with its interlocking web of economic, political, psychological, and other factors. Under these conditions of extreme complexity, which are typical of most real-world systems, it is rarely the case that people can ever meet the bar for blameworthiness described above [Blaming people for their poor economic decisions]. .. . . Questions about the attitudes that we ought to have towards others are psychological and moral in nature. But they are also politically significant. *How we regard those who end up less fortunate informs how we address social inequality, and the extent to which we care about it* (Emphasis mine. Davies, 2021[2]).

Endemic poverty is a consequence of sustained structural disadvantage and cannot be attributed to individual psychology. As Moghaddam (2010) has argued, the excessive psychologizing of the human condition in Western public culture has reduced the range of explanations for prevailing conditions primarily to personal attributions without considering shared history and community experience. It is as if everything that happens in a lifetime can be reduced to psychological causes in a single lifetime. Such approaches to explain poverty, by blaming the poor for their condition, in fact best serve neo-liberal policy, social and political leaders, especially those who may be held responsible for persistent poverty conditions. If the poor are blamed for their situation, and for perpetuating poverty, it keeps responsibility of corporate houses, societies and governments at bay. The slogan that the poor are doing something wrong is easier to deal with than acknowledging collective political and social failure in addressing poverty contexts. Failed programmes and ineffective policies can be blamed on unjust attitudes. This is one of the most serious injustices of our times since the people promoting a cause are guilty of holding deep and enduring prejudices that they may carry forward from their own cultures. Perhaps one that will be better judged by future generations.

Research in the field of economics has recently raised a debate about such attributions. Economists Mullainathan and Shafir (2013) argue behaviours that are commonly associated with the poor like poor attention at school, unwise financial decisions or impulsive conduct are in fact likely to be the products of scarcity rather than its cause. If poverty, hunger and scarcity persist, a person's behaviour is seriously impacted negatively. These findings in fact overturn our assumptions that the poor are poor because they have bad attitudes. In fact, they have been found to make poor decisions because they live with scarcity. By examining several research studies, Mullainathan and Shafir (2013) prove that the main cause for making poor decisions in cases of economic distress is that scarcity predisposes people to taking unwise decisions.

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[2] The mathematical case against blaming people for their misfortune | Psyche Ideas.

Policy

As Davies argues in her essay, how we view poverty is a social and moral issue, but it also has significant political impact on the way the less fortunate are understood and what we do about it (Davies, 2021). Policies in developing countries are largely based on human capital models derived from economics, combined with a narrow view of linear human development which is drawn from Western developmental psychology and tends to focus exclusively on family experiences and individual disposition and ignore contextual, social, historic and community level factors. This combination is in danger of overlooking many factors that impinge on people's lives, such as class, gender, poverty status, factors that are underpinned by political economic structures, and forms of inequality, as is discussed in the previous section. The assumption of humanitarian aid, early childhood and family interventions seems simple, but can it be justified? The assertion is if the poor start behaving differently, if they start living like 'us', they will no longer be poor, and the next generation will transition into a more prosperous life. This is the basic promise that existing evidence-based family interventions claim when family practices are the target of welfare activity. In the health sector, possibilities to avoid infections are based on the practice of supporting health and hygiene, and the same template is used for social, emotional, cognitive, language and other domains. A significant amount of evidence from research on poverty using ethnography is ignored in making such policy statements. After all, as international aid staff argue, they have a 100 odd countries where they need to implement their policies, how can they attend to cultural differences? Yet, without attending to cultural difference, the primary objective of welfare work cannot be fulfilled. We need an alternate conceptualization of children and families living with poverty. An image that treats people as vital, decisive human beings who are trying to make the best of a difficult situation. It is hard to accept the arrogance behind the assumption that we know best what is good for them, since living under those conditions would be extremely difficult for people on the other side, if not impossible.

Derived from the expert position is a view that the poor need assistance in bringing up children on account of inadequate resources and incapability. How poverty is defined and what counts as inadequate has also been a problematic issue on account of ecological, cultural, social and historical differences, but we will not go into this discussion here except to say that people's economic status cannot always be attributed to their 'attitudes' as is commonly assumed.

Defining Poverty

There is no denying that living with poverty is unfavourable and can even be damaging for people, especially the most vulnerable, women and children. However, the jury is still out about what exactly poverty is and how it should be measured.

Poverty reduction is an urgent, pivotal goal for humanity, but few are agreed about what poverty is and the gap between normative notions and experienced poverty.

The original list of 'basic human needs' as defined by the Bristol team included: Absolute poverty is a condition characterized by deprivation of basic needs and deprivation is a continuum from mild to extreme. By this estimate, the number of children living in poverty is 400 million! These needs include food, safe drinking water, sanitation facilities, health, shelter, education, information and access to services.

For instance, "children living 20 km or more from any type of school or 50 km or more from any medical facility with doctors. Unfortunately, this kind of information was only available for a few countries, so it has not been possible to construct accurate regional estimates of severe deprivation of access to basic services" (Alkire et al., 2014, p. 2).

Regarding what can be done to end poverty, automatic and sweeping connections that are made between poverty, fertility, criminality and poor-quality childcare are overstated if we scrutinize the available literature on poverty. After all, as I have argued, being poor is not just a matter of disposition, there are historical, regional, structural and social factors.

What concerns us as social scientists is how such interventions have been initiated in the absence of sufficient scientific evidence. How has the cultural sovereignty of people been compromised so effortlessly? Does such an intervention not dilute the rights of the family and reach beyond the agenda of poverty alleviation? How can welfare agencies provide a guarantee that their interventions and the subsequent changes that they claim to have made do not in fact compromise the adaptive mechanisms that people develop in particular contexts in order to survive. The context of poverty or disadvantage is not likely to change as quickly as behaviour might. Changing practices can, in fact, predispose families and children towards unanticipated vulnerabilities. There is no doubt here that the confidence of the counsellors, the change agents, derives from a background of relative affluence and the corresponding poverty of the people they work with. It seems quite clear that the poor also lose their rights to privacy and self-determination on account of being poor.

Key Debates in Poverty Status

The field of poverty studies has a range of key debates that have not yet been resolved. Here is a brief list of the unresolved tensions between experienced poverty and explained poverty, using Berger and Luckmann's classic distinction in social construction (1966/1991).

Absolute/Relative Poverty line or calorie intake versus corrected for local standard of living (Alkire et al., 2014). Absolute poverty is a condition of acute deprivation in the form of severe food insecurity, premature death, ill-health, illiteracy, homelessness, lack of clothing, etc., measured on the basis of nutrition or income. Relative poverty is when a person is regarded as poor in comparison to other persons in his or her society (Gweshengwe & Hassan, 2020). Knowledge about the absolute or relative nature of poverty is essential to analysis of poverty. People in poverty are commonly classified as 'very poor', 'poor' and 'near poor or vulnerable' (Alkire et al., 2014; Banerjee et al., 2009). On 20 October 2020, the Government of India released a Working Paper focussing on the fact that post-pandemic definitions of poverty need to be modified to include housing and other facilities that permit physical distancing (Ghildiyal, 2020). Economic status is thus highly sensitive to events such as these:

Dimensional/Multidimensional Single index like income or multiple factors like access to services. Poverty has multiple dimensions—financial, economic, social, political, health, environmental and seasonal—which interlink with and reinforce each other (Alkire et al., 2014; Gweshengwe & Hassan, 2020).

Consumption/Capability Amartya Sen (2005) highlighted that definition should also focus on capability and not just on consumption,;poverty has a thousand faces'.

Poor are seen through the singular lens of what *they do not have rather than what they have*, it is as if their lives are empty of all other resources, culture, tradition, identity, dignity, self-respect, vitality and sovereignty (Singh, 2015).

Mind the gap between normative poverty and experienced poverty. Thinking you are poor versus being labelled as poor. People do not necessarily see themselves as 'poor'. Poverty is almost always labelled from the outside. Internally, people compare themselves with others around them, 'We have 100 goats, they have 10'.

Deprivation overlaps with poverty, difference is: deprivation is a *situation of the individual and describes the lack of access to basic rights and fundamental freedoms* agreed upon. While poverty refers to *lack of resources*, deprivation refers to an actual condition that deprives people of the satisfaction of basic material, social and psychological human needs. Distinction is highly relevant for children (Alkire et al., 2014; Gordon et al., 2003).

Has poverty increased, remained the same or decreased? In this regard, there have been significantly fewer famines and droughts in present times in comparison with the past (Pinker, 2018). In addition to these points, there are different perspectives on poverty depending upon the disciplinary affiliation and these need to be considered while understanding poverty.

Gaps in the Literature

The debates listed above highlight the many gaps in the literature of poverty. Although we are aware that poverty is disadvantageous to the poor everywhere, but context and causes are different in different settings. Consequences of poverty are assumed rather than known, except perhaps for extreme deprivation.

Assumptions like children of the poor make poor parents and repeat cycles of poverty and violence do not find support in research. If we consolidate research on reasons for poverty, we find that systemic poverty is the largest cause of deprivation, especially in developing nations. Location, distance, remoteness and underdevelopment are primary causes of poverty like conflicts and lack of support. Despite this, policies in most cases are based on the assumption that poverty is an outcome of poor choices, although these have been recently challenged by economists (Mullainathan & Shafir, 2013). Sufficient evidence that systemic poverty is related to unsupportive policies: Zip code politics[3] and unavailability of loans to African Americans in the US, for instance.

The Practical Application of Psychological Research

Calls to change the status quo on the way psychological principles are applied worldwide, span decades (e.g., LeVine & Norman, 2001), with more recent appeals pointedly demonstrating the potential harm of such a bias towards communities living outside of the affluent West (Arnett, 2008; Henrich et al., 2010). Bhatia (2018) argues that Euro-American psychological science has adopted a dominant and imperial position to the extent that it speaks for and represents most of humanity. The shift from 'evidence-based' to 'ethics-based' policies that this volume argues for applies well here since welfare policies for family-based and centre-based services for women and children draw directly on evidence from research in developmental psychology, like the importance of the early years, attachment theory and the like. The nature of this evidence is however deeply rooted in Western culture and ideology and may not apply even in the West (Henrich, 2020). For people living in other parts of the world where cultural practices, beliefs and attitudes depart dramatically from the West (Chaudhary, 2004), the problem becomes a serious one. Furthermore, even within other countries, there is diversity and distance between ethnic groups, social classes, regions and religions, adding to the endless dynamics of contextual diversity.

When we work with the poor, within-country biases further exacerbate marginalization, making it essential to go beyond the material-cultural dichotomy that swings between the discourse of deprivation and relativism, beyond pity and anger, and recognize the perseverance of the people in the face of depleting resources and to treat that as evidence of vitality and the will to survive under difficult circumstances. Welfare and aid should be provided as basic services, on grounds of human dignity, equity, and respect and not handouts.

Although teaching and research in psychology have been increasingly impacted, the consequences of social science research on practices have received little

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[3] https://www.revealnews.org/article/for-people-of-color-banks-are-shutting-the-door-to-homeownership/.

attention. In fact, family and child welfare programmes, especially those funded by international NGOs, campaign for intervention for social change based on Euro-American ideals of community living, family dynamics and children's development drawing from traditional perspectives in developmental psychology and child development, with little or no attention to culture and ecology. In fact, whenever culture is considered, it is focused only on 'how to get the message across' and not 'what messages are meaningful' (Chaudhary, 2018, p. 536). These policies have profound impact on the ways in which services are presented to people ranging from school experiences, youth programmes, care of children and health and family welfare.

Globally inspired attempts at poverty alleviation have not worked on account of several reasons, in fact, may even have had unanticipated consequences for people that can cause an imbalance, as the instance of language and cultural loss of indigenous tribes in India demonstrates when State languages are imposed on minority groups (Gupta & Padel, 2021). Given that the poor (rural, tribal, islanders) live in such a delicate balance with their ecology, interventions can lead to other consequences. Structures of oppression are perpetuated with welfare programmes that derive from a sense of superiority and claims to having the answers to people's problems, and in fact, even creating problems where there are none.

Beliefs and practices of local people are either opaque to Western-trained researchers and practitioners or marginalized by them because of the (assumed) risk that these beliefs and practices have on children's healthy and successful developmental trajectories. Add to that the dimension of poverty and people become instantly classified as incapable and inept, to be saved by the ways of the affluent. These researchers' well-intentioned efforts to improve the health and well-being or intelligence and language of children disregard and often interfere with communities' ways of living that are ecologically and culturally grounded and they neglect the real-world consequences of their recommendations that may, in fact, result in exacerbating the very condition that poverty alleviation endeavours are targeted towards.

Why Applications in Psychology Lag Behind

Applications in the field of psychology search for universal standards so that applications can be seamlessly transferred across the globe. In the case of developmental psychology, it has been argued that the notion of childhood, its sequence and setting described in textbooks, draws from a specific ideology as several articles have noted (Henrich et al., 2010; Nielsen et al., 2017). The world's people are described by using repeated investigations from a small group of people. As a reflexive discipline where scientists attempt to understand themselves, this is a luxury psychology cannot afford.

In poverty alleviation programmes, many of the large-scale efforts derive from mainstream psychology rather than local scholarship and cultural knowledge. So, whereas academic psychology in India may have developed some indigenous trends, applications still rely on a certain kind of mainstream psychology that persists without critical examination about cultural relevance or ecological validity. Applications in education, welfare and theory are the main examples here. There are several reasons for this. The market economy and corporate world is firmly aligned towards selling products, and simple, measurable, packaged ideas are far more accessible than doubts and debates. Furthermore, applications like standardized tests and intervention programs require funding that international agencies can afford, whether these are publishing houses or NGOs. Psychological counselling and therapy draw heavily from Western theories and models that are available.

In application, even more so than in academic psychology, complexity is eschewed and findings that fit an agenda are given precedence. As mentioned at a recent conference[4] by a UNICEF representative Raghavan (2019), 'We have to provide the same message to 300 odd countries, and that challenge itself requires a simplification of the message'.

Poverty is a matter of global concern, and a responsibility of every collective agency accountable for the welfare of citizens of a country, the provision of which should be advanced with an adequate understanding of the dynamics of disadvantage. Social and economic factors such as basic education, healthcare and employment are important not only in their own right but also for the role they can play in giving people opportunity to approach the world with courage and freedom (Sen, 1999). The vulnerability of disadvantaged groups adds to the obligation of policy makers. Movements that emphasize free markets to lower poverty have accelerated in recent years and attracted the attention of businesses, academics and public officials. This approach explicitly views the poor as resilient and creative entrepreneurs and value-conscious consumers. This romanticized view of the poor is also flawed and harms the poor in two ways, resulting either in too little emphasis on legal, regulatory and social mechanisms to protect them or create an overemphasis on micro-credit and under-emphasis on boosting modern enterprises that would provide employment opportunities in addition to grossly under-emphasizing the critical role and responsibility of the state for reduction of poverty (Karnani, 2007).

With regard to labelling people as 'illiterate', Kumar (2018) argues that calling people 'uneducated' when they have never been to school because they did not have opportunity or access is unjustifiable because it leaves no room for distinguishing between school refusal and lack of access. Such nuanced understanding of disadvantage is a key to ethical practice since it prevents further displacement on account of positioning and stereotyping.

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[4] IACCP Regional Conference held at University of Costa Rica, San Jose, Costa Rica, July 16–19, 2019.

Mind the Gap Between the Field and the Lab

Psychology is dominated by research findings from Western, Educated, Industrialised, Rich, and Democratic, now popularly known as WEIRD samples (Henrich, 2020). As opposed to the ease with which lab studies can be conducted in Western universities where infrastructure and equipment are available, several local conditions make lab studies hard to achieve in Indian universities, and field-based studies are more practical. Fewer spaces, long distances, ideological differences and other issues come in the way of organizing lab studies. Especially for children and families, research often requires people to reach the homes of participants rather than expecting them to come to the lab. Other than university students, a well-researched group, other adults and children can be found either at their workplace or homes. Psychology research is delimited by the use of language. Most research scholars prefer to carry out research in English, but that is mostly not possible. This is especially so when we look at research in therapy and counselling. For instance, the lexicon of available emotion words in languages other than English is rarely available for students, which increases the challenge for them to work with a non-English-speaking client or respondent.

Furthermore, conditions at home are quite different from those in the lab, and face-to-face interactions are not commonplace. There are culturally familiar ways of interacting (Keller, 2007), and these can have profound impact on the ways in which interactions are structured and interpreted, often interfering with participation in research.

The field is replete with the continuity of real experiences rather than representations of which the research encounter is just a slice. Furthermore, reluctant adults, suspicious gatekeepers, uncertain transportation, health issues, family life and fearful children make the lab a difficult arrangement. Homes are accessible and easy, but quite different, not conducive to individual interactions because these are characterized by multilogues, and individual assessment/interviewing is suspect ('Why do you want others not to speak?'). For example, play with people guides play with objects and objects belonging to others are particularly avoided for fear of spoiling and breaking. It is hard to keep children shackled to a situation, they run away, especially in rural and tribal areas which are characterized by open spaces and free movement of children.

Here again, issues related to ethics become more relevant than simply looking at the evidence, since the latter would require an examination of how the evidence was collected and interpreted.

Psychology for Social Justice and the Urgent Need to Address Applications

The earth is telling us that evidence-based ideas emerging from modernism are not sustainable for the long-term safety and survival of life on earth (Ghosh, 2019). To become aware of the consequences of our decisions and actions, we must question everything and conduct thorough reviews of the ways in which science has been applied. This is true for physical as well as the social sciences. Practices that use the results of psychological research must regularly audit all transfer of knowledge to applications: measures, methods, therapies and interventions (Burman, 1996). The lens must be expanded and culture/context needs to be viewed as constitutive, with the acceptance towards multiple solutions rather than singular models, and democratize the research process where International collaborations should be enforced and trust researchers, in addition to reducing gatekeepers, reducing expenses, promoting horizontal collaborations, increasing openness, publicizing widely—formal and informal, organizing debates and conferences around Institutional Ethics Committees and IRBs (Institutional Review Boards). Improving the quality of local publications, reducing the need to refer to Western research studies and picking up topics relevant to the culture and people are all important paths for development. As scholars, we must adopt humility and keep ethics alongside evidence, since the latter has been known to lack contextual perspective. Unlike the natural sciences, human activity has to be seen through the position of thinking, feeling subjects each with their own framework and unique life circumstances. We are who we have become because of who we study; respect for participants is key to ethical standards. Simply getting documents signed for ethics clearances is not enough. Participants' lives are more important than our work and remembering that participants have a right not to engage with our projects is critical. Issues that are outcomes of global policy must be engaged with as debates. For instance, issues of child protection for immigrants are direct outcomes of simple applications of psychology research. The shift from evidence-based to ethics-based standards is thus key to a more justifiable agenda for psychology.

What is needed is, and we use Oppong's words here, 'epistemic authenticity with the view to ensuring that the conceptions of reality … reflect authentic African socio-cultural realities but not an imposed or self-imposed contrived reality borrowed or derived from the West' (2019, p. 298). Engaging with 'others' in all steps of practice—interdisciplinary and inter-cultural collaborations, intersectionality, social justice—is necessary as is the re-examination of positions on poverty and affluence. A renewed focus on 'ecological wisdom' and people's right to self-determination and meaning is the need of the hour and therein, developing applications (in learning, therapy, aid) that do not have 'subtractive' impact on people. This can be achieved by strengthening attention to alternative meanings, methods and discourses.

The recent pandemic has highlighted our vulnerability as we stand at the crossroads between unprecedented possibilities and escalating exclusions. I strongly believe that psychology offers reason and opportunity to foster enduring, strong, genuine, collaborative and trusting international academic alliances. International associations and horizontal collaborations have important roles to play toward social justice in the practice of psychology. To make significant changes, perhaps we must work like 'detectives to first discover key ideas behind well-referenced discourse flow of persuasive rhetoric" where theoretical arguments have become replaced with "links with literature' (Valsiner, 2019, p. 431). We must find strategies to break away from these links (evidence or otherwise) and join the movement towards a collaborative and comprehensive science of human psychology. Such endeavours are not merely new emergent branches of psychology but consist of an enterprise to position research in ways that are adequate and appropriate for studying complex and changing aspects of human phenomena by breaking away from the axioms of the physical sciences (Valsiner, 2019) and the hegemony of mainstream psychology.

Psychology of and for the people living in diverse worlds needs to be reconstructed, reorganized and re-conceptualized. Through this chapter, I have made an attempt to focus on how different institutional structures (colonies, empires, universities, lobbyists, markets) have constrained innovative explorations of culturally constructed psychological phenomena, where human dignity and social justice are primary principles of scholarly engagement. Lessons in research methods need to reflect this shift from reliability to validity and authenticity! In the pursuit of a cultural science with focus on deep psychological inquiry, one aspires for a psychology that is liberating and democratic, allowing multiplicity of content, form and approach to reach beyond suppressed meanings and flattened discourse.

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Chapter 14
Afterword

Birthe Loa Knizek

Through 12 far-reaching chapters, scientists and clinicians have explored what ethics-based practice means. They have shown both in thorough reflections and in practical examples the necessity of renewed thinking and abandonment of slavish following the criteria of evidence-based practice. In 2005, Maya Goldenberg directed our attention to the problems inherent in evidence-based ethics by looking at how evidence-based practice mostly is understood as 'the empirically-adequate standard of reasonable practice and a means of certainty', and she claims that this displaces the normative discourse:

> . . .evidence-based ethics suggests a moment of inattentiveness to the normativity of moral decision-making. Recognition of the plurality of values and meanings in operation complicates our use of moral and ethical terms and categories; however, the quick turn to various truth-producing strategies labelled 'empirical' that has taken place warrants careful consideration. While the 'empirical turn' in bioethics signals a need for reconsideration of the methods used for moral evaluation and resolution, the options should not include obscuring normative content by seemingly neutral technical measure. (Goldenberg, 2005, p. 8)

Decision-making, which is embedded in moral pluralism, seems to be mediated by scientific rigour from a positivist perspective resulting in generalisation and insufficient context sensitivity. Before Goldenberg Goodman (2003) stated that the intersection of ethics and evidence must be understood as an instance of ethical decision-making in contexts of scientific uncertainty as evidence always is subject to uncertainty. The challenge thus seems to be twofold: both to accept the uncertainty related to evidence and not weak-willingly attribute it to all situations and contexts. Both parts demand courage: courage to accept the limitations of science and own knowledge, as well as courage to think out-of-the box and practice outside national guidelines, which might have legal consequences. In this volume, where scientists

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and clinicians from different areas have emphasized the need for ethic-based practice, central aspects of evidence-based practice have been problematized. In the first part of this volume, Sven Hroar Klempe and Tor-Johann Ekeland have layed the foundation of the following contributions in their basic reflections on logic, science, evidence and ethics. Their arguments are in line with Goldenberg and Goodman. While Klempe from a theory of science standpoint takes a closer look at the association between science and logic and problematizes the gap between thought-based knowledge on one side and experiential knowledge on the other, Ekeland takes a step closer to practice elucidating the implicit moral claims in evidence-based practice. He makes a strong argument opposing the fundamental idea of defining what can be regarded as legitimate knowledge resulting in best practice, and he shows how increased inhumanity might be the result of evidence-based practice. His chapter functions as the pivotal point for understanding the following chapters.

In the next part of the volume, the focus is on ethical challenges in methods. In general, 'evidence-based' implies a hierarchy of methodologies, where 'the trustworthiness or validity of evidence is a function of the design of the study from which the evidence is obtained (...) there is a consistent placement of randomised controlled trials or the systematic review of them at the top, retrospective studies well down the list, and clinical anecdotes are seen as providing little if any evidence for the evaluation of the intervention' (Goldenberg, 2005, p. 3). This epistemological claim has, however, consequences, as it results in intervention criteria, where one-size-fits-all. The generalization of 'evidence' and the implicit subject construction have huge consequences for many individuals. John-Arne Skolbekken in his chapter on type 2 diabetes problematizes how one within an evidence-based risk discourse identifies high-risk individuals and transfers personal responsibility to them for maintaining their own health. The universal human, where all are treated alike, consequently burdens these high-risk individuals with a lifelong diagnosis with inherent shame and blame, while contextual factors seem overlooked. Ekeland's claims of inhumanity seem further supported by Skolbekken's example.

Katrina Jaworski on the other hand focuses on methods and ethics in research and questions the demarcation line between researcher and researched in the production of data. She argues that both parts equally are implicated in the relationship between research ethics and ontology. In her unstructured interviews with queer young people, she demonstrates that research ethics in this situation are about ontology as much as about practical issues. She here raises already the question of an existential dimension in the encounter between individuals, and her chapter is much in line with Klempe's basic reflections on how science and logic are connected and how language carrying personal interest always is involved. His demand for honesty seems met by Jaworski. From her chapter, there is a very small leap to the next part, which is about ethical challenges in interventions/therapy illuminated by the next four chapters. Stordahl and colleagues in a study among clinical psychologists found that the existential dimension of therapy seems central in their work with specific patients and that they base their reflections on experiential knowledge. It seems that these psychologists in their initial reflections go beyond formal demands of evidence-base and prioritize their experiential knowledge and feelings.

Following, Daniele Bruzzone goes even further into the existential dimension reminding us that both patients and caregivers face radical questions about the meaningfulness of life when confronted with a crisis. He exemplifies this through the application of logotherapy in a meaning-centred group therapy conducted with cancer patients, where he proves that investing in meaning and values acts as a psychological protective factor and a therapeutic resource in coping with illness. Meaning-making is a personal process, which hardly can be directed by criteria for evidence-practice but nonetheless is a valuable resource in activating psychological resources. Bruzzone in his chapter shows important alternatives to evidence-based practice. Birgit Nordtug and Cathrine Grimsgaard in the next chapter focus on the needs of children with parents suffering from mental disorders and/or drug abuse. They explore the possibility of establishing an ethics-based practice by means of narratives, where one can meet children's basic human need for care and their desire to be taken seriously as meaning-making subjects. Their work is clearly an attempt to counteract inhumanity produced by manual-based approaches and to reinstall dignity and humanity for these children.

Picione, Freda and Savarese present a new model Sense of Grip on chronic disease (SoGoD) that aims at overcoming the dichotomy between evidence and ethics-based approaches by integrating normative frames and subjective processes in a semiotic perspective. Through the analysis of the narrative construction of a chronic disease, personalized styles of sensemaking can be uncovered and personalized interventions initiated. With this chapter, we get an important theoretical alternative to reductionistic evidence-based models.

Focus on the impossibility of neglecting the context of individuals is the through going topic in this volume on ethics-based practices. Studying and helping living people ethically includes awareness, attention and willingness to recognize their living conditions. It is not possible to ignore the global ecological, financial, political interconnectedness and interdependency, as well as the influence of social media on cultures. However, the inherent notion of a universal human in evidence-based practices seems even more obscured when confronted with different cultures. The next part of this volume consequently is devoted to ethical challenges on a global basis. Knizek and colleagues in their chapter take a critical look at the Global Mental Health movement's efforts to improve mental health for people living in under-resourced settings by transferring evidence-based practices from Northern contexts to remarkable different Southern contexts. Because of the inattentiveness to the contextual differences, critics have pointed out that this might have unethical consequences by pathologizing individuals rather than their socio-political-economic conditions. Both Global Mental Health supporters and their critics have good intentions and strong ethical standpoints with unforeseen consequences that go against their initial ideals. The main message of this chapter is the need for constant critical self-reflectiveness regardless initial good intentions in order to avoid the pitfalls Ekeland initially pointed out. Ikuenobe goes even further into the necessity of understanding local perceptions of personhood and attitudes as prerequisite for contextualized ethics-based practices in healthcare and suicide prevention. He demonstrates that the African sense of personhood consists of social-moral aspects and bio-physical, psychological and metaphysical aspects and involves the internalization of communal norms and moral principles. This conception of personhood with the important role that community and relationships play in the attainment of well-being is relevant for understanding the issues of health, well-being and suicide among Africans, which must inform possible interventions. Evidence consequently cannot be transferred without consideration of the normative and ideological context.

From the overall reflections on African personhood as necessary basis for health interventions, we get a very illustrative insider perspective on challenges for disenfranchised gender and sexual minorities in Uganda from Kibuka Musoke and Hama-Owamparo. In a hostile psycho-political and legal system that limits and violates the human rights of gender and sexual minority groups, these persons have a set of challenges; access to competent healthcare with friendly and knowledgeable professionals seems limited compared to the need expressed by individuals within this community. The authors in this perspective chapter on disenfranchised gender and sexual minorities highlight the role of functional meaning in the determination of better mental health and overall well-being. Their chapter is an important contribution to how one can assure basic human rights in a hostile context. What worth has evidence-based practice in this context, which is not a unique exception worldwide and what alternatives do therapists have to ensure the rights and well-being of their clients? While Kibuka Musoke and Hama-Owamparo illuminate the crucial importance of the local context, which sometimes can be devastating, Chaudary focuses on the impropriety of transference from Western-based evidence base to the Global South raising serious questions about the validity of the evidence itself on account of ideological foundations, methodological bias and ecological variation. She concludes that ethics-based practices must include global-local dynamics in the transfer of knowledge to local contexts. Again, we see that when local context is ignored and combined with the assumption of ‘evidence’ as a universal common ground for psychological practices, this creates a fallacy, which is counterproductive and might have damaging consequences.

Hence, the aim of this volume has been to reveal the shortcomings of evidence-based practice and explore the grounds for ethics-based practice, as ‘evidence-based decision-making faces inherent limitations insofar as only certain kinds of experience can be quantified and only certain questions explored’ (Goldenberg, 2005, p. 7). The authors of this volume together have pointed out enough indicators to show that evidence-based practices are insufficient. Moreover, they have drafted both alternative models and approaches for ethics-based practices. Yet, these contributions are just the beginning in a process of achieving an ethics-based practice in healthcare. Thus, we hope this volume can trigger the development of further alternatives in theory, research and therapy.

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