Culture – Risk – Health.

Culture-sensitive approach towards health literacy, health communication and risk in the fields of preventive and predictive medicine.

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Mariya Georgieva Lorke

aus Haskovo, Bulgarien

mmXpress, Münster

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Betreuerin:	Prof. Dr. Dr. Saskia Jünger
Gutachter*in:	Prof. Dr. Elke Kalbe Prof. Dr. Christian Albus

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In ihrer Arbeit *Risk as a forensic resource* schreibt Mary Douglas: *“No risk item will normally be considered in isolation. Nor does intellectual activity happen in isolation.”* Dieses Zitat trifft den Kern vieler thematischer Schwerpunkte meiner Dissertation ebenso wie den Kontext ihrer Entstehung. In der Zeit der Pandemie verlangte die Auseinandersetzung mit Risiko und Kultur ein besonders hohes Maß an Reflexion – wissenschaftlich wie privat. Das Schreiben in den Phasen von Lockdowns fügte dem Konzept der Isolation eine weitere Dimension hinzu, die die britische Sozialanthropologin so vermutlich nicht gemeint hat. Umso größer ist das Bedürfnis für mich, all denjenigen einen Dank auszusprechen, die mich bei diesem Vorhaben ideell, kommunikativ und ganz praktisch unterstützt haben: Ohne sie wäre dies nicht möglich gewesen.

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Summary of the PhD Thesis: Today's predictive and preventive medicine provides individuals with many opportunities to regulate and control their health through the early detection of serious illnesses, patient-centred therapy or preventive measures. Nevertheless, such technical innovations and the emphasis on risk also challenge individuals, professionals and society in multiple ways, each of which opens space for the re-negotiation of moral, cultural, practical and communication matters. A perspective embracing cultural matters in the context of meaning making on risk and health is therefore essential, though it is still underrepresented in the research landscape. To address this entanglement of values, meanings and health issues in the context of risk and health literacy, an interdisciplinary and empirical approach is needed. The current PhD thesis aims at contributing to this multitude of research demands by providing foundation for the better understanding of the intertwining between the symbols and meanings of risk and health, revealed through a symbiosis of socio-anthropological and health sciences approaches.

The innovative core of this thesis addresses health literacy and risk in the field of predictive and preventive medicine in a culture-sensitive way, both on the level of *content* and *methodology*. Put into practice, this not only means understanding more about the effects of culture on health literacy and risk prediction, but also raising cultural awareness in all phases of the research process through the on-going reflection on culture as shared understandings, values and practices in which risk and health literacy are embedded. Based on this, the leading question of the work is: *What makes a culture-sensitive approach to health literacy and risk in predictive and preventive medicine?*

The current thesis draws on conclusions of three included articles on health literacy in the context of risk, providing an exemplary cross-section of the complex entanglement of (a) risk types (e.g. genetic or mental), (b) their impacts on the body and mind, and (c) the role of communication in the negotiation of meanings. Each of these articles derives from qualitative empirical research among persons at risk of developing certain diseases (familial breast and ovarian cancer, Alzheimer's disease, psychosis, and cardiovascular disease). Inspired by the call for more participatory (or collaborative) research in the field of health literacy and risk, the study design of the project which the included contributions derive from is based on narrative interviews (n=34). The analysis strategy was based on the theoretical framework of the Reflexive Grounded Theory, and allowed for elaborating themes, concepts and meanings which may have remained underrepresented in existing definitions and conceptual works.

Gaining more understanding for individuals' explanatory models of risk and health in the context of their lifeworlds adds additional layers of understanding risk in medicine which need to be reflected on. That is why the conceptualisation and operationalisation of health literacy in the context of risk both in research and in preventive and predictive practice may benefit from a culture-sensitive approach which enables the process of risk negotiation or the balancing of mismatching agendas. Approaching risk counselling as an intercultural encounter may increase awareness of the different cultural significances of risk and the narratives which define them, and may improve communication skills. Furthermore, sharpening sensitivity for the various cultural meanings of risk in health also contributes to increased critical health literacy as well as to a broader critical approach in terms of the distribution of power and blame.

With respect to future research on health literacy and risk addressing culture in a narrower sense (in terms of nationality, ethnicity, or migration background), this thesis also invites for a renegotiation of concepts of vulnerability, and offers practice-oriented recommendations for approaching these concepts in diversity-sensitive contexts. Regarding implications for practice, this thesis contributes to existing research both in providing concrete insights which may be integrated into counselling practice and risk communication, as well as a framework (for professional trainers and educators) for the development of educational units in the field of vocational training and personnel development.

Zusammenfassung der Dissertation: Die moderne prädiktive und präventive Medizin eröffnet für Ihre Patient:innen eine große Bandbreite an Möglichkeiten, die eigene Gesundheit zu beobachten und zu kontrollieren: mithilfe der Früherkennung schwerer Erkrankungen, patient:innen-zentrierter Therapie oder präventiver Maßnahmen. Nichtsdestotrotz bringen solche technischen Innovationen sowie ein verstärkter Fokus auf Risiko viele Herausforderungen mit sich – für die betroffenen Personen, Professionelle im Gesundheitswesen und die Gesellschaft im Ganzen – und eröffnen Räume für die Neuverhandlung moralischer, kultureller, praxisbezogener und kommunikativer Fragestellungen und Themen. Um diese Verflechtung von Werten, Bedeutungen und Gesundheitsthemen im Kontext von Risiko und Gesundheitskompetenz zu adressieren, ist ein interdisziplinärer und empirischer Zugang erforderlich. Ferner ist eine kultur-sensible Perspektive (d.h. die Kultur als gemeinsame Verständnisse, Werte und Praktiken in Bezug auf Risiko und Gesundheitskompetenz zu reflektieren) – bislang in der Forschungslandschaft noch unterrepräsentiert – essenziell. Diese Dissertation bietet eine mögliche Antwort auf diese Forschungsanforderungen und offeriert Eckpfeiler für ein besseres Verständnis für die Verflechtung von Symbolen und Bedeutungen von Risiko und Gesundheit: Diese Überlegungen werden mittels einer Symbiose aus sozial-anthropologischen und gesundheitswissenschaftlichen Zugängen dargelegt.

Der kultursensible Umgang mit Gesundheitskompetenz und Risiko im Bereich der präventiven und prädiktiven Medizin – sowohl auf inhaltlicher als auch auf methodischer Ebene – bildet den innovativen Kern dieser Arbeit. In der praktischen Umsetzung bedeutet dies nicht nur eine Untersuchung der kulturellen Auswirkungen auf Gesundheitskompetenz und Risiko, sondern auch eine Verankerung des kulturellen Bewusstseins in allen Phasen des Forschungsprozesses. Darauf aufbauend lautet die leitende Forschungsfrage der Arbeit: *Was macht einen kultursensiblen Umgang mit Gesundheitskompetenz und Risiko in der prädiktiven und präventiven Medizin aus?*

Die vorliegende kumulative Dissertation basiert auf drei inkludierten Artikeln zur Gesundheitskompetenz im Kontext *Risiko*, die einen exemplarischen Querschnitt durch diese komplexe Verschränkung von Risikotypen (z.B. genetisch oder psychisch), deren Auswirkungen auf Körper und Geist und die Rolle der Kommunikation bei der Aushandlung von Bedeutungen bieten. Grundlage für die drei unterschiedlichen Beiträge ist eine qualitative empirische Studie unter Personen mit einem erhöhten Krankheitsrisiko in unterschiedlichen Erkrankungsfeldern (familiärer Brust- und Eierstockkrebs, Alzheimer, Psychosen und koronare Herzkrankheiten). Inspiriert von der Forderung nach mehr partizipativer (oder kollaborativer) Forschung im Bereich der Gesundheitskompetenz und der Risikoforschung basiert das Studiendesign des Projekts, aus dem die enthaltenen Beiträge stammen, auf narrativen Interviews (n=34). Die Analysestrategie wurde basierend auf dem theoretischen Rahmen der reflexiven Grounded Theory entwickelt und ermöglichte die Herausarbeitung von Themen, Konzepten und Deutungen, die in bestehenden Definitionen und konzeptionellen Arbeiten bisher unterrepräsentiert geblieben sind.

Ein besseres Verständnis für die individuellen Erklärungsmodelle von Risiko und Gesundheit im Kontext verschiedener Lebenswelten fügt zusätzliche Ebenen der Risikokompetenz in der Medizin hinzu, die es zu reflektieren gilt. Deshalb kann die Konzeptualisierung und Operationalisierung von Gesundheitskompetenz im Risikokontext sowohl in der Forschung als auch in der präventiven und prädiktiven Praxis in hohem Maße von einem kultursensiblen Ansatz profitieren, der den Prozess der Risikoaushandlung oder des Ausgleichs divergierender Agenden ermöglicht. Die Annäherung an die Risikoberatung als interkulturelle Begegnung kann das Bewusstsein für die unterschiedlichen kulturellen Einbettungen von Risiko und die sie definierenden Narrative schärfen und die Kommunikationsfähigkeit verbessern. Darüber hinaus trägt eine verbesserte Sensibilität für die verschiedenen kulturellen Einbettungen von Risiko in der Gesundheit auch zu einer erhöhten

kritischen Gesundheitskompetenz sowie zu einem erweiterten und kritischen Zugriff in Bezug auf Machtverhältnisse und Schuldzuweisungen bei.

Im Hinblick auf künftige Forschungen zu Gesundheitskompetenz und Risiko, die Kultur im engeren Sinne thematisieren (also im Sinne von Nationalität, Ethnizität oder Migrationshintergrund), lädt diese Arbeit auch dazu ein, die existierenden Konzepte von Vulnerabilität neu zu verhandeln. Sie bietet auf diese Weise praxisorientierte Empfehlungen für den Umgang mit Risiko und Gesundheitskompetenz in verschiedenen diversitätssensiblen Kontexten.

Auf einer praxisorientierten Ebene liefert diese Arbeit konkrete Erkenntnisse, die erfolgreich in die Beratungspraxis und die Risikokommunikation integriert werden können. Sie kreiert damit auch einen Rahmen für die Entwicklung von Bildungseinheiten im Bereich der beruflichen Bildung und Personalentwicklung für professionelle Trainer:innen und Dozent:innen der Erwachsenenbildung.

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1. INTRODUCTION

Today's predictive and preventive medicine provides individuals with many opportunities to regulate and control their health through the early detection of serious illnesses, patient-centred therapy or preventive measures. Nevertheless, such technical innovations and the emphasis on risk also challenge individuals, professionals and society in multiple ways, each of which opens space for the re-negotiation of moral, cultural, practical and communication matters. In the context of risk, these matters mark a pendulum swing in the search for a balance between confidence and threat, control and uncertainty, competence and responsibility, abstract data and everyday experiences. Such movements do not take place in a vacuum, but are marked by social, cultural, and individual values (Lengwiler und Madarász 2010). This is why it is essential to call attention to the *context* of meaning making and knowledge production in the field of risk.

In order to address the question of how these values, meanings and health issues are intertwined in the context of risk and health literacy in predictive and preventive medicine, an interdisciplinary and empirical approach is needed. The current PhD thesis aims at contributing to this multitude of research demands, by providing a foundation for the better understanding of the entanglement of symbols and meanings revealed through a symbiosis of socio-anthropological and health sciences approaches. Furthermore, this work suggests a possible path for transforming the theoretical interpretations into practice-oriented ideas in the field of vocational training and personnel development.

1.1 TOPIC, BACKGROUND, AND CONTENT

The discussed pre-occupation with risk and uncertainty in modern societies (Beck 1992; Bröckling 2017) permeates the fields of medicine, technology and health, delivering developments which mirror the moral concepts, social ideals and common values of a certain shared culture. In the realm of medicine, this is particularly relevant for the field of predictive and preventive medicine, which is characterised by constant innovations and is primarily future-oriented. On the one hand the field mirrors the *kind* of values and morals which determine technological and scientific progress (e.g., attitude towards health and disease, control over uncertainty, early prevention over high risk of disease); on the other hand, this field also mirrors the *ways* of transforming uncertainty into knowledge and communicating it to others (e.g., by means of statistical calculations in the context of evidence-based medicine). The context in which this transformation process is embedded and takes place is shaped by a certain culture[A] - for predictive and preventive medicine, this is the culture of biomedicine. Such cultural centrism (or dominance of one specific culture regarding the definition and interpretation of health risks) calls for socio-anthropological reflections on the costs it may cause in medical practice *on a social level* (e.g., distribution of blame for not responding to early prediction offers, or exclusion of certain groups from predictive and preventive practices due to high complexity of the health system or language barriers), and in everyday experiences *on an individual level* (e.g., preoccupation with risk which may impact life-planning and well-being). It is also worth asking if and how these costs can be reduced, while maximizing the benefit for both affected individuals and professionals. Despite its economic connotation, this question contains a strong moral dimension of *how a predicted risk can be negotiated in the fields of responsibility, access to healthcare, diversity and informed decision-making*.

On a theoretical level, this complex interplay of values, meanings and interdependencies can be approached by re-defining and re-operationalising concepts like health literacy, health communication, patient-centeredness, and shared decision-making. In this way space can be made for a socio-anthropological perspective on already more or less established definitions and models in the field of health sciences. In order to give due attention to the cultural context (in terms of shared understandings, values and practices and not solely equating with ethnicity or nationality) in which these perspectives are embedded, a research approach for a *non*-culture-centric examination is needed. Such an approach may be inspired and informed by the long-standing tradition of cross-cultural research and its aspiration of avoiding ethno-centrism. Since ethno-centrism is an attitude “deeply rooted in the human mind” and characteristic for most societies (Bizumic 2018), it is essential to reflect on it at all stages of the research process. Even though this attitude is mostly connected with ethnicity (Bizumic 2018), this thesis addresses ethno-centrism as a group’s self-centred thinking in the context of health literacy and risk. Since looking at culture as an extended term, cultural groups are here structured around specific beliefs, values and language (such as the medical world and lay people, scientists and practitioners, western and non-western societies, or minorities and majorities).

In the current research project, the notion of ethno-centrism needs to be reflected on in the following two key dimensions:

(1) Due to the fact that the concepts of health literacy and risk have their theoretical and academic anchoring primarily in western societies, they may be critically

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[A] The term culture is used in its extended meaning, which includes medical culture, culture in terms of nationality or ethnicity, lifeworld etc. The use of the term and the definition of the concept will be discussed in detail in the next chapter **1.2 Terminology and concepts.**

seen as *per se* ethno-centric, western-dominated constructs (Ingleby 2012). Employing a culture-sensitive approach in the research on health literacy and risk means critically reflecting on the notion of superiority in the context of ethno-centrism (Bizumic 2018) and providing space for the negotiation of meanings, assumptions, beliefs and convictions.

(2) The health literacy and risk research landscapes are dominated by differentiated group-specific knowledge and beliefs, such as scientific definitions or statistical models. Since this knowledge is produced and discussed in tight professional circles it is also essential to reflect on this group-centred thinking and to integrate diversity-awareness in all phases of the research process.

Sticking to this notion of ethnocentrism, it is fruitful to align the research design to the following questions in the context of risk in predictive and preventive medicine: Can health literacy and risk be understood as culture-sensitive concepts, or does their western- or medicine-centric imprint potentially lead to a mismatch of agendas (between patients and doctors and between western and non-western societies)? Do health literacy and risk enable and facilitate access to the health system, or are they more concerned with a shifting of responsibility and blame? How does health communication affect decision-making? Which culture-sensitive ways of encouraging empowerment are possible?

The current project aims to illuminate the different dimensions of these questions. The investigation is grounded in the three aforementioned articles on health literacy in the context of risk, which provide an exemplary cross-section of this complex entanglement. As already stated, each of these articles derives from qualitative empirical research among persons at risk of developing certain diseases, and provides insights into the field of health literacy and risk:

Lorke, Mariya*; Harzheim, Laura*; Woopen, Christiane; Jünger, Saskia (2020): **Health Literacy as Communicative Action-A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine.** In: *International journal of environmental research and public health* 17 (5). DOI: 10.3390/ijerph17051718.

Lorke, Mariya*; Schwegler, Carolin*; Jünger, Saskia (2021): **Re-claiming the Power of Definition—The Value of Reflexivity in Research on Mental Health at Risk.** In: Maria Borcsa und Carla Willig (Eds.): Qualitative Research Methods in Mental Health. Innovative and collaborative approaches. Cham: Springer, pp. 135–165.

Lorke, Mariya*; Harzheim, Laura; Rhiem, Kerstin; Woopen, Christiane; Jünger, Saskia (2021): **The ticking time-bomb. Health literacy in the context of genetic risk prediction in familial breast-ovarian cancer. A qualitative study.** In: *Qualitative Research in Medicine & Healthcare* 5. DOI: 10.4081/qrmh.2021.9647.

In the current PhD thesis, the findings of these three articles condense into a list of insights on health literacy and risk from a socio-anthropological point of view. They emphasise the role of culture, and encourage more culture-sensitive research in this field. Furthermore, the insights will be translated into a practice-oriented module-box which can be used by professionals in the field of education for the development of workshops and vocational training for risk communication, cultural awareness and person-centeredness.

1.2 TERMINOLOGY AND CONCEPTS

Due to the interdisciplinary character of the current PhD thesis and the multifaceted concepts which structure both the research and the theoretical argumentation, it is essential to provide a foundation for the definitional anchoring of the main terms and concepts. In the following sections, the key pillars of reasoning at the centre of the included articles' discussions – on *culture, health literacy, patient-centeredness and intercultural opening* – will be briefly summarised and related to each other.

Definition of culture

The word *culture,* as used in the title of this work, requires a definition. Though an overwhelming number of definitions of culture exist in the humanities and social sciences, it is neither possible nor useful to elaborate on each of them in this thesis. Rather, in order to look at culture from different perspectives within the field of predictive and preventive medicine, both a practical *and* a systems-oriented definition is needed. In 2014, *The Lancet* published a work suggesting a broad view on culture in the context of the health system. This view defines culture as "the shared, overt and covert understandings that constitute conventions and practices, and the ideas, symbols, and concrete artefacts that sustain conventions and practices, and make them meaningful." (Napier et al. 2014). As such, the view provides the perfect foundation for the stance adopted in this thesis.

In the specific context of the current thesis, culture refers to (1) a *bottom-up* (individual) level, which concerns not only the cultural background of the patients (in terms of nationality, ethnicity, language use, social, educational and economic background, etc.) but also the culture of their doctors. The concept of culture also serves (2) the *top-down* (systemic and social) dimension, referring to the culture of medicine as shared understandings. This understanding of culture implies that each patient-doctor-encounter is a kind of intercultural encounter (Kleinman 1978) which is embedded in a specific cultural context, i.e. that of medicine and science. This dual understanding of culture allows me to refer to the term both when taking the different emic[B] and the etic[C] perspectives.

[B] inner perspective: the self-understanding and self-attributions of the group about themselves.

[C] outer perspective: the understanding and attributions which are projected to the group by outsiders.

Not only patients have culture

Since the complexity of healthcare is continuously expanding, while societies are becoming increasingly diverse, culture is gaining importance as a factor which impacts doctor-patient-communication, shared decision-making, health care and disease management. For the current research, it is essential that culture should not be reduced to the concept of *migration background* in the field of health research, since this implies that patients bring culture through immigration into the health system without necessarily reflecting on the culture which already exists in the medical environment. Neglecting culture in medicine would automatically lead to poor quality of the health services (Napier et al. 2014), which is why it is essential to address cultural awareness in health from the perspectives of the culture of the individuals, and that of their doctors.

Culture and patient-centredness

With a view to the extended definition of culture in the context of this thesis, another related concept in the field of medicine comes into play: *patient centeredness*. When there is talk of incorporating patients' lifeworlds (Schütz und Luckmann 1979) into the consultation practice, an immediate connection to patient-centeredness is made. Why then is it not enough to employ this concept when researching health literacy and risk, instead of making use of such a broad concept like culture? The following three dimensions reveal the most important facets of the answer to this question:

(1) First and foremost, the concept of patient-centeredness does not sufficiently encompass the culture of the doctors and the health system, and thus it may – in the context of this research – misleadingly reinforce the notion that "only patients have culture" (Napier et al. 2014) and doctors not.

(2) Second, the concept of patient-centeredness is strongly connected to *agency*. There are many different definitions of patient-centeredness in healthcare which have also been used in connection with terms like patient participation and patient empowerment (Castro et al. 2016). In this context, health literacy may be seen as an enabler for patient-centeredness (Scholl et al. 2014), and patient-centeredness seen as a precondition for achieving patient empowerment (Castro et al. 2016). If in the context of the current research only the concept of patient-centeredness were employed, a power imbalance may be reinforced, whereby the individual health literacy of a patient may serve as an excuse for an organisation to withhold patient-centred care and thus hinder patient empowerment.

(3) Third, many empirical studies on patient-centeredness indicate limitations concerning their research design. These limitations originate in the predominance of conceptual definitions from North America and Europe (Scholl et al. 2014). There is no sufficient evidence

that patient-centeredness can be successfully applied in non-WEIRD[D] societies (Henrich et al. 2010). Employing the concept of culture seems to be more fruitful for the aims of this PhD project.

Re-defining health literacy

The third aspect concerning the concept of patient-centeredness mentioned above also invites for a reflection on existing conceptualisations of *health literacy,* and for a short detour explaining the use of the term in this work. The statements made about health literacy in this thesis are oriented towards a broad definition which, on the one hand, relies on the integrated model of Sørensen et al. (2015) and, on the other hand, opens up space for the perspectives of individuals; this combination attempts to connect theoretical considerations to everyday experiences. This thesis does not intend to measure or quantify the level of health literacy in the context of risk; it rather aims at illuminating different dimensions of the concept using a qualitative empirical approach. Since in this research field there is a close relationship between system and individual, the power of (mismatching) definitions on risk, health and disease is challenged, and the need for more participatory research is confirmed.

Considering healthcare in highly diverse societies, the intertwining between system and individual also engages the concept of the *intercultural opening* (Schröer 2007) of a health organisation on a systemic level. Of note, Rosenbrock (2016) relates the concept to *health literacy,* describing them as “two ways to the same goal”. The same assumption underlies the recommendations of the National Action Plan on Health Literacy, which suggests bringing organizational health literacy and intercultural opening together and implementing them on a broad scale (Schaeffer et al. 2018). In the same vein, this thesis proposes an integrated approach, increasing cultural awareness among professionals, supporting culture-sensitive communication about risk, and thereby contributing to health-competent organisations. The field of risk in predictive and preventive medicine may serve as a test field for operationalising such an encompassing approach, and may contribute to reducing complexity of future conceptualisation and evaluation processes of similar interventions.

The complex entanglement of the concepts which build the theoretical background of this thesis also reveals their hegemonic power in the different disciplines. This power also discloses one central critical point of such interdisciplinary undertakings situated between theory, practice, and politics (especially when related to minorities) – *the power of interpretation*. This doctoral project does not aim at examining in detail all these huge and often controversial concepts and notions but rather to outline the reasoning scheme according to which the concepts

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[D] Western, Educated, Industrialized, Rich, and Democratic (WEIRD) societies may be illuminated and related to each other and thereby reflecting on the impact of interpretation. This reflexive approach is particularly taken into account in this thesis through the perspective of those being studied. Similarly to Lorig et al. (2012), who suggests that “if a service is to be patient centered, then both the health care system and the patient have to be involved in determining what this means. Each has its own view of meaning, and patient centered care will never be achieved if patients are not part of the solution” (p. 524). The current research on health literacy and risk emphasises the individuals’ active role in the process of meaning making, regarding both risk and health literacy as illuminated in a specific system-context.

1.3 STATE OF RESEARCH

An isolated look at the concepts and ideas mentioned above may justify the question of what is actually new, and what may be merely “old wine in new bottles” (Tones 2002) in this thesis. Both the long-lasting and deeply ingrained tradition of research on risk in social anthropology, and the increased research interest in health literacy and health communication during the last decades, challenge the theoretical anchoring of the topic in a rich, multidisciplinary research landscape. In line with Hoydis’ (2021) argument (who sees *risk* as a *boundary object* employed differently in the various research disciplines), the current research on health literacy and risk (in their respective cultural embeddings) may be seen as a cluster of *boundary objects* in an interdisciplinary field. A detailed description of the state of research is provided in the respective publications incorporated in the current thesis. In the following, only those fields will be outlined which help to illuminate the innovative value of this work and to provide anchor points in this interdisciplinary research area.

The concept of risk in the tradition of anthropological research finds significance as a concept strongly related *to* and done *by* culture. It starts with (1) classical anthropological research into how various societies interpret, value and live risk (Evans-Pritchard 1988; Lévi-Strauss und Heintz 1955; Malinowski 1999); moves through (2) theoretical, interpretative and analytical works which provide categories for intercultural comparison as well as frameworks for defining the relation between risk and culture (Boholm 2003; Douglas 2002; Durkheim 1915), and arrives at (3) the present studies that examine, for example, concrete risk understandings in medicine-dominated environments (Heibges 2019; Konrad 2003; Polzer 2010; Samerski 2011; Samerski und Henkel 2015).

In the field of health communication, the concept of health risk is often explored from a perspective concerned with accuracy. A whole strand in communication and literacy science focuses on the ways individuals interpret risk statistics and on the prevention of potential deficits through improved written and verbal risk communication, education or training. The vast majority of these works emphasises the *correct* in terms of risk literacy (Wacker et al. 2020; Lein und Jenny 2020; Petrova et al. 2019; Hinneburg und Ellermann 2020; Jenny et al. 2018), i.e. accurate mathematical and statistical understanding and comprehension of the risk scores. The current work is grounded on the assumption that *correct* mathematical comprehension does not automatically lead to *more competent* decision-making on prevention, and aims at illuminating the interplay of other factors which enable decisions on risk, and relates them to the broader context of meaning making in terms of risk and health.

While my thesis builds on the traditional anthropological approaches in research on risk, it also innovatively links risk to health literacy (as a set of individual abilities and attitudes, coping strategies and decision- making in health), which is a step beyond the concept of risk literate decision-making solely based on accurate understanding.

As with risk literacy, the tendency to quantify and measure the *literate* and *non-literate* ways of dealing with health can be also observed with respect to the concept of *health literacy* which has received increasing attention during the last decades. Health literacy is defined as a set of abilities which individuals need in order to navigate successfully through the health system and manage their health or disease (Sørensen et al. 2012). A great number of studies aim at quantifying these abilities, offering different ways to measure them on a functional level using questionnaires based on self-assessment in relation to the handling of health information (Schaeffer et al. 2016), or performance-based measures[E]. However, a gold standard for assessing health literacy currently does not exist (Kiechle et al. 2015). Nevertheless, these different facets, measured by the instruments mentioned above, also point to the different sub-concepts which increasingly get attention in research and practice: (1) looking at health literacy beyond the notion of accuracy and correct interpretation of health information in terms of critical health literacy (Chinn 2011); (2) addressing health literacy by paying attention to the organisational dimension of the concept (Farmanova et al. 2018); (3) opening up space for freely retrievable health information in terms of digital health literacy (Huhta et al. 2018; Tennant et al. 2015); (4) investigating health literacy among specific groups (Aldin et al. 2019; Bröder et al. 2017) or (5) in the context of specific conditions (Kilfoyle et al. 2016; Magnani et al. 2018; Okan et al. 2020; Palumbo 2015).

Apart from the thematic layer briefly summarised above, three different groups of research on health literacy may be roughly defined on a methodological level: (1) quantitative

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[E] e.g. Short Test of Functional Health Literacy in Adults [S-TOFHLA] ((Parker et al. 1995)), the Rapid Estimate of Adult Literacy in Medicine [REALM] ((Davis et al. 1993)), and the Schwartz and Woloshin numeracy questions ((Woloshin et al. 2001));

studies, which are concerned with defining, measuring and quantifying a certain set of abilities in single individuals or whole populations (Rikard et al. 2016; Schaeffer et al. 2016; Sørensen et al. 2015; Svendsen et al. 2020); (2) qualitative studies exploring the concept of health literacy and its determinants from the perspective of those being studied, based on lived experiences in the context of certain health issues (Bollars et al. 2019; Parisod et al. 2016; Wolf et al. 2005), specific groups (Fiedler et al. 2019) or generally while dealing with health information (Jordan et al. 2010; Matas und Bronstein 2018); and (3) literature reviews as well as studies focusing on theory development (Chinn 2011; Nutbeam 2008; Nutbeam et al. 2018; Sørensen et al. 2015). Although the number of qualitative or mixed-methods studies has increased in the last ten years, quantitative and primarily deductive studies dominate the research field. The novelty of the current thesis, therefore, is its emphasis on health literacy and risk in its interactional dimension, i.e. its grounding in qualitative data which takes the perspective of those being studied.

The innovative character of this thesis also lies in the aspiration to address health literacy and risk in the field of preventive and predictive medicine in a culture-sensitive way, both on *thematic-* and *on methodological levels*. To illuminate what this looks like in practice, an example from the research of Rowlands et al. (2017) will be used. The authors offer a model of health literacy as a "journey of health" based on "lived experiences". In contrast to other models (Nutbeam 2008; Paasche-Orlow und Wolf 2007; Sørensen et al. 2012), theirs has its starting point within the categories "ethnicity/culture" and "family health history". These two categories also mirror the cultural sensitivity employed in the current thesis, which takes (1) a top-down culture-sensitive perspective on the concept of health literacy in which culture is the embedding factor for analysis, and (2) a bottom-up perspective rooted in individuals' lived experiences. Such culture-encompassing approaches are scarce in the research field.

While health literacy and health risk (and their prediction and prevention) are widely seen as inseparable within the health system, critical discussion on the dominance of one culture over another in the process of meaning making is still underrepresented. Similarly, research in the context of health literacy and risk from a *cultural perspective* is rare. Those works which do address aspects related to culture may be roughly grouped in four different categories:

(1) studies which concentrate on health literacy or understanding of risk among people with so called *migration background* (Adam und Carol 2020; Aldin et al. 2019). The notion of culture here is related to ethnicity or/and nationality. Researchers found that 'insufficient' health literacy among this population may affect or be affected by diverging values regarding health, poor proficiency of the local language (Binder et al. 2012), missing system-relevant

knowledge (Hughson et al. 2018), or social status (Chang 2019). As such this extremely heterogeneous group is often labelled as vulnerable (Messer et al. 2015);

(2) research which concentrates on the culture-specific understandings on health and risk and on the development of culture-specific communication strategies, which aim at addressing health topics in a culturally responsive way (Bollars et al. 2019; Koduah et al. 2019; Rheault et al. 2019). These approaches offer ground for intercultural research and invite reflection on objectivity, subjectivity and culture on an abstract level. Due to the high complexity of the field and the immense diversity of identities, lifeworlds and experiences, the applicability of culture-specific solutions remains selective and highly limited;

(3) studies with a more implicit relation to culture and which encompass works from the field of patient-centred communication and care, or a certain medical culture or the culture of health (Barton et al. 2018);

(4) studies which emphasise the notion of diversity in health care (Hayes et al. 2020).

This PhD thesis offers a culture-sensitive approach on all levels of research from the definition of the research questions, through the methods of research to the practical implications. It takes a culture-encompassing – instead of culture-specific – approach to health literacy and risk in the field of predictive and preventive medicine. Thus, culture is not considered as an object of research, but more as a research instrument and a framework of analysis. This socio-anthropological approach towards health literacy and risk in predictive and preventive medicine represents an innovation in itself, which, according to the best of my knowledge, has not yet been pursued.

1.4 RESEARCH QUESTIONS

A topic situated at the crossroads of so many different theoretical and practical disciplines, demands research questions that address matters which are both specific and general, moral and practical, and subjective and objective, and which take the perspectives of individuals as experts on their own health risks. The main research question *What makes a culture-sensitive approach to health literacy and risk in predictive and preventive medicine?* encompasses different facets of both theory generation and practical implications in the fields of diversity, health communication and values related to health risk and responsibility, and will be operationalised throughout the following paragraphs with reference to the respective included articles.

The current thesis builds on three contributions which address exemplarily specific sub-questions and aims at generating additional findings through an intersectional analysis. The project takes into consideration (1) the relevance of patients' risk perceptions for their health-related behaviour, (2) the ways of communicating these explanatory models of risk, and (3) the cultural framework of professional knowledge on risk embedded in the health system.

The first included article (Lorke et al. 2020) answers the questions: How can a *culture of risk* among persons at risk be described? Does it diverge from the culture in biomedicine? If yes, in which way? Furthermore, the article illuminates the concepts of health literacy and risk from a bottom-up perspective, emphasising the role of patient-doctor communication in empowering health literacy.

The second article (Lorke et al. 2021b) deepens the previous question and looks at the way this culture can be specified and described when the concept of risk concerns the individual's mind and mental health. The contribution emphasises the notion of vulnerability, and addresses the definitional spaces between scientific risk understanding and individuals' meaning making concerning risk in the context of mental health. It also elaborates on methodological considerations concerning the process of designing and doing research in the context of risk and mental health. This perspective also encompasses culture on different levels: the culture and ethics of research, the medical culture of risk, and the culture of narrating risk.

The third article (Lorke et al. 2021a) looks at risk from a bodily perspective – in terms of genetic risk. The article examines risk as closely connected to the body and emphasises the fluid border between the understanding of genetic risk and *the disease hidden in the body*. It also addresses the definitional spaces between scientific risk understanding and individuals' meaning making of risk, by drawing on narratives of lived experiences and family history. The conclusions in this paper refer to the concept of critical health literacy.

The current thesis sets out to provide insights on how knowledge about risk cultures can be applied to improve both (1) individual and organisational health literacy in the context of risk, and (2) health care provision (in the field of predictive and preventive medicine) in highly diverse societies.

1.5 METHODOLOGICAL APPROACHES

Inspired by the call for more participatory (or collaborative) research in health literacy and risk, the study design of this project is based on an explorative inquiry using narrative interviews, and incorporates an interdisciplinary approach (social anthropology and health sciences). The analysis strategy was developed based on the theoretical framework of *Reflexive Grounded Theory* (Breuer et al. 2017) and allowed for elaborating themes, concepts and meanings which may have remained underrepresented in existing definitions and conceptual works. Such an inductive approach enriches the research field and opens it up for further disciplines – particularly for social- and cultural anthropology. The different methodological steps of data collection and analysis are described and evaluated in the included contributions and will therefore not be repeated in this chapter.

2. SUMMARY OF FINDINGS AND INTERSECTIONS

In the following sections the content of the included articles and the individual contribution of the PhD candidate will be outlined, and the analysis of the articles' findings will be illuminated. The thematic and methodological intersection between the included articles will be clearly arranged (Table 2) and the theoretical considerations behind the article selections will be explained.

2.1 KEY DATA OF THE INCLUDED ARTICLES AND AUTHOR CONTRIBUTIONS

The current thesis is based on three contributions originating from the project RisKomp[F]. In this chapter the key data and publication status of the contributions will be outlined and the authors' contributions will be illuminated. Furthermore, a detailed description of the individual contribution of the PhD candidate to each of the included articles will be provided.

Table 1: Key data and publication status of the contributions of the cumulative dissertation

	Key data	**Status**
Contribution 1	Lorke, Mariya*; Harzheim, Laura*; Woopen, Christiane; Jünger, Saskia (2020): **Health Literacy as Communicative Action - A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine**. In: *International Journal of Environmental Research and Public Health* 17 (5). DOI: 10.3390/ijerph17051718.	published in 2020
Contribution 2	Lorke, Mariya*; Schwegler, Carolin*; Jünger, Saskia (2021): **Reclaiming the Power of Definition - The Value of Reflexivity in Research on Mental Health at Risk.** In: Maria Borcsa und Carla Willig (Eds.): *Qualitative Research Methods in Mental Health. Innovative and collaborative approaches*. Cham: Springer, pp. 135–165.	published in 2021
Contribution 3	Lorke, Mariya*; Harzheim, Laura; Rhiem, Kerstin; Woopen, Christiane; Jünger, Saskia (2021): **The Ticking Time-Bomb. Health Literacy in the Context of Genetic Risk Prediction in Familial Breast-Ovarian Cancer. A qualitative study.** In: *Qualitative Research in Medicine & Healthcare* 5. DOI: 10.4081/qrmh.2021.9647.	accepted

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[F] Health Literacy of Persons at Risk – From Information to Action (RisKomp) 01/2016-12/2020
Cologne Center for Ethics, Rights, Economics, and Socials Sciences of Health (ceres), Universität zu Köln
URL: https://ceres.uni-koeln.de/en/research/projects/riskomp
Funding institution: Robert Bosch Stiftung (Funding number: 11.5.A402.0002.0)

Table 2 summarises the authors' contributions to the research and writing of the three contributions.

Table 2: Author contributions (in alphabetical order):

	Contribution 1	**Contribution 2**	**Contribution 3**
Conceptualization	L.H., **M.L.,** S.J.	**M.L.**, C.S., S.J.	**M.L.**
Formal analysis	L.H., **M.L.,** S.J.	**M.L.**, C.S., S.J.	**M.L.**
Funding acquisition	C.W.		C.W.
Investigation	L.H., **M.L.,** S.J.	**M.L.**, C.S., S.J.	L.H., **M.L.,** S.J.
Methodology	L.H., **M.L.,** S.J.	**M.L.**, C.S., S.J.	L.H., **M.L.,** S.J.
Project administration	C.W.		C.W.
Supervision	S.J.	S.J.	S.J.
Validation	L.H., **M.L.,** S.J.	**M.L.**, C.S., S.J.	L.H., **M.L.,** S.J.
Visualization	L.H., **M.L.**	**M.L.**, C.S., S.J.	**M.L.**
Writing -original draft	L.H., **M.L.**	**M.L.**, C.S., S.J.	**M.L.**
Writing -review and editing	C.W., S.J.	S.J.	K.R., C.W., S.J.

The following table (Table 3) details the individual contribution of the PhD candidate.

Table 3: Individual contribution

1	Lorke, Mariya*; Harzheim, Laura*; Woopen, Christiane; Jünger, Saskia (2020): **Health Literacy as Communicative Action-A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine.** In: *International Journal of Environmental Research and Public Health* 17 (5). DOI: 10.3390/ijerph17051718.	The research design of the project underlying this article includes four different clinical fields. In order to manage the large amount of qualitative data, my colleague L.H. and I shared the responsibility of conceptualising data collection and analysis, developing the methodological framework, organising the recruitment process, and conducting the interviews. S.J. supported and supervised our activities and was involved in all research phases. In the process of data analysis, I was primarily responsible for the data in the fields of familial breast and ovarian cancer and psychosis, while L.H. focused on Alzheimer's disease and coronary heart disease. L.H. and I conceptualized the design of the article, developed the theoretical model grounded in the findings, and wrote the original draft. My individual intellectual contribution was the idea to conceptualise health literacy as communicative action and to refer to the corresponding Habermasian theoretical framework. C.W. and S.J. lent their expertise to editing the draft. L.H. and I prepared the manuscript, including visualisations, for publication and were responsible for the communication with the journal.

2	Lorke, Mariya*; Schwegler, Carolin*; Jünger, Saskia (2021): **Re-claiming the Power of Definition - The Value of Reflexivity in Research on Mental Health at Risk.** In: Maria Borcsa und Carla Willig (Eds.): *Qualitative Research Methods in Mental Health. Innovative and collaborative approaches*. Cham: Springer, pp. 135–165.	This article is based on two different projects. It originated from a collaborative conference panel and emphasises the process of doing qualitative research on risk in mental health. All authors were involved in the conceptualisation, analysis, investigation, methodology, validation, visualisation and writing of the article, and assumed responsibility for three different approaches: I was responsible for the development of the ethnological approach, C.S. for the linguistic one and S.J. for the sociology of knowledge perspective. The article is based on empirical data from two projects; it was my responsibility to generate and discuss the findings in the field of psychosis.
3	Lorke, Mariya*; Harzheim, Laura; Rhiem, Kerstin; Woopen, Christiane; Jünger, Saskia (2021): **The ticking time-bomb. Health Literacy in the Context of Genetic Risk Prediction in Familial Breast-Ovarian Cancer. A qQualitative Study.** In: *Qualitative Research in Medicine & Healthcare* 5. DOI: 10.4081/qrmh.2021.9647.	Based on the data collected by means of the methodology developed in collaboration with S.J. and L.H. at the beginning of the project, it was my responsibility to conceptualise the article, analyse and discuss the empirical data, write the original draft, develop its visualization, and prepare the manuscript for publication. L.H. and S.J. supported the process in validating the data; together with C.W. and K.R. they reviewed and edited the manuscript.

Further relevant publications:

Harzheim, L.* & Lorke, M.*, Jünger, S. (2021), **Potenziale unterschiedlicher qualitativer Forschungszugänge für den Erkenntnisgewinn in der Gesundheitskompetenz-Forschung.** In: Okan O. & Rathmann K. (Hrg.) *Gesundheitskompetenz.* Springer Reference Medizin & Pflege – Therapie – Gesundheit (submitted)

Harzheim, L.*, Lorke, M., Rostamzadeh, A., Jessen, F., Woopen, C., Jünger, S.: (2021): **Health Literacy in Persons at Risk for Alzheimer's Disease – a Qualitative Research on Patient's Perceptions in the Context of Predictive Medicine.** *Qualitative Research in Medicine and Healthcare* (submission planned 10/2021)

2.2 RESEARCH SCOPE OF THE CUMULATIVE THESIS

In the following section the reasons for selecting the three contributions will be illuminated, and the structure of and research process behind this thesis will be outlined.

As a first step, the contributions were selected according to the following criteria: (1) illuminating different types of risk – genetic risk of familial breast-ovarian cancer (Lorke et al. 2021a) and risk of developing psychosis (Lorke et al. 2021b). The selection also mirrors aspects of both physical and mental health, offering two perspectives on health risk based on the notion of body-mind dualism; (2) exploring the research approach to risk both on a methodological (Lorke et al. 2021b) and content level (Lorke et al. 2020); (3) encompassing the perspectives of individuals at risk (Lorke et al. 2021a; Lorke et al. 2020; Lorke et al. 2021b) and researchers in the field of health at risk (Lorke et al. 2021b). The binding elements between the articles are those which are relevant for a culture-sensitive approach towards health literacy in the context of risk – the process of meaning making on risk, and its critical assessment based on reflections on communication and risk-knowledge both in the context of the health system and individuals' everyday life and experiences. Table 4 summarises this field of thematic and methodological intersections.

Table 4: Thematic and methodological intersections

Research question	This research project addresses the complex interrelation between health risk and health literacy, taking into consideration (1) the relevance of patients' risk perceptions for their health-related behaviour, (2) the ways of communicating these explanatory models of risk, and (3) the cultural framework of professional knowledge on risk embedded in the health system.		
Research article	**Health Literacy as Communicative Action - A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine.**	**Re-Claiming the Power of Definition - The Value of Reflexivity in Research on Mental Health at Risk.**	**"The Ticking Time-Bomb". Health Literacy in the Context of Genetic Risk Prediction in Familial Breast and Ovarian Cancer – a Qualitative Study.**
Topic and perspectives	Different perspectives on risk and the way they are related to health literacy Health literacy in the context of risk as communicative action – strategic communication and critical health literacy	Addressing definitional spaces between scientific risk understanding and individuals' meaning-making of risk in the context of mental health The notion of vulnerability	Addressing definitional spaces between scientific risk understanding and individuals' meaning-making of risk in the context of genetic testing The concept of critical health literacy
Specific sub-questions	How can a *culture* of risk among persons at risk be described? Does it diverge from the culture in biomedicine and if yes, in which way? ➡	How can this *culture* be specified when the concept of risk concerns the mind and mental health? ➡	How can this *culture* be specified when the concept of risk concerns the body in terms of genetic risk?
	Communication	***Mind-body dualism***	
Focus of analysis	Illuminating the concepts of health literacy and risk from a bottom-up perspective	Risk perceptions, meaning making and vulnerability in the context of risk prediction in mental health	Risk perceptions, identity, stress and responsibility in the case of genetic risk prediction; coping strategies
Practical implications	Cornerstones for the development of tools supporting health risk communication	Checklists for doing research on risk in the field of mental health	Cornerstones for the development of tools for promoting health literacy in the field of genetic testing (communication and shared decision making)

As a second step, a content analysis of the findings- and discussion-sections of the included articles was carried out in order to identify overarching *insights*. These were further developed and analysed using existing literature and theoretical frameworks, yielding recommendations for their practical implication in the field of health communication and for future research.

As a third step, these insights and recommendations were transformed into learning objectives for health professionals in the field of predictive and preventive medicine, which may be one step on the way to building a culture-sensitive organisation. These learning objectives were then related to the empirical data, and possible methods of achieving them in a specific educational or training situation were offered. The main outcome of this process is a module-box for professional trainers and educators which may be used for the development of learning units in the field of risk and health communication.

2.3 MAIN FINDINGS OF THE INCLUDED ARTICLES

The main findings of all three articles will now be briefly synthesised, with a focus on the aspects which pertain to the respective research question of this thesis. A short overview of the methods and materials, as well as the main conclusions, will be also provided.

2.3.1 THE CULTURE OF RISK: HEALTH LITERACY AS COMMUNICATIVE ACTION

Article 1: Lorke, Mariya*; Harzheim, Laura*; Woopen, Christiane; Jünger, Saskia (2020): **Health Literacy as Communicative Action-A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine.** In: *International Journal of Environmental Research and Public Health* 17 (5). DOI: 10.3390/ijerph17051718.

The first article addresses the understandings of risk among individuals at risk of developing certain diseases. The contribution examines the meanings of risk, the definitional space between ‘healthy’ and ‘ill’ and the process of health-related decision-making. The article accentuates the diverging meanings of risk and their importance in the context of biomedicine and in individuals’ everyday lives and experiences. The leading question of the contribution is: *How do the condition of ‘being at risk’ and individual health literacy interrelate?*

The study design employs a bottom-up ethnographic and health sciences perspective on health literacy (critical health literacy understood as the ability to appraise the credibility of the risk information, assess its applicability for the individual situation, and challenge its meaning in the context of the individual lifeworld). The contribution draws on empirical qualitative data, collected using narrative interviews with 34 persons at risk in four clinical fields (familial breast and ovarian cancer, Alzheimer disease, coronary heart disease and psychosis). The inclusion and exclusion criteria were defined in collaboration with colleagues from the University hospital of Cologne. The researcher team (LH, SJ and ML) organised the interviews, and collected and analysed the data. The data collection took place in the period between 04/2018 and 09/2019. The recordings of the interviews were transcribed and analysed.

The findings in this article are embedded within theoretical approaches dealing with power relations and communication in healthcare encounters. They demonstrate the great importance of interaction in the context of health literacy and risk and emphasise the role of the communication process between doctors and advice seekers. When interpreted within

Habermas' theory of communicative action (Habermas 1981), the findings reveal the necessity of sufficient understanding between the culture of risk in biomedicine and in patients' lifeworld.

In the context of the overarching research question of this thesis, this article provides encouraging ground for perceiving health literacy in the context of risk as an intercultural interaction, in which adequate and non-hierarchical communication on risk is inevitable for the process of decision-making. Promoting critical health literacy in the context of risk is a means of increasing awareness of the role of strategic communication in risk counselling. As far as implications for practice are concerned, this article provides cornerstones for the development of tools which may support communication between doctors and patients, and so improve health literacy both in its organisational and personal dimension.

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Article

Health Literacy as Communicative Action—A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine

Laura Harzheim [1,*], Mariya Lorke [1,*], Christiane Woopen [1,2] and Saskia Jünger [1]

[1] Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health (CERES), University of Cologne and University Hospital of Cologne, Universitätsstraße 91, 50931 Cologne, Germany; christiane.woopen@uni-koeln.de (C.W.); saskia.juenger@uni-koeln.de (S.J.)

[2] Research Unit Ethics, Institute for the History of Medicine and Medical Ethics, Faculty of Medicine, University of Cologne and University Hospital of Cologne, Universitätsstraße 91, 50931 Cologne, Germany

* Correspondence: laura.harzheim@uni-koeln.de (L.H.); mariya.lorke@uni-koeln.de (M.L.)

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Abstract: Predictive and preventive medicine play an increasingly important role in public debates on health, providing cutting-edge technologies with the potential to measure and predict individual risks of getting ill. This leads to an ever-expanding definitional space between being "healthy" and being "ill", challenging the individual's everyday life, attitudes and perceptions towards the self and the process of health-related decision-making. "How do the condition of 'being at risk' and individual health literacy interrelate?" is the leading question of the current contribution. Drawing on empirical qualitative data, collected by means of narrative interviews with persons at risk in four clinical fields, a bottom-up ethnographic and health sciences perspective on health literacy (with an emphasis on critical health literacy) is employed. The findings will be embedded within theoretical approaches dealing with power relations and communication in healthcare encounters, particularly Habermas' theory of communicative action. The core outcome of our study is a concept for an overarching model of health literacy in the context of health-related risk prediction across indications, based on empirical insights gained through interpretative analysis of the four clinical domains.

Keywords: health literacy; persons at risk; ethnographic approach; health sciences; qualitative research; perceptions of health and disease; critical health literacy; shared decision making; communicative action

1. Introduction

Being confronted with a health risk entails the solicitation to deal with risk-related information. When conducting research on the phenomenon of being at risk, it is therefore important to consider the evolving possibilities of predictive and preventive medicine, and their effects on individual needs with respect to information and support in decision-making processes. Communication between health care professionals and persons at risk is an essential element in this course. In the following, we wish to briefly introduce the meaning of the notion of 'being at risk', the role of health literacy, and the relevance of interpersonal communication in the setting of predictive medicine.

1.1. Being at Risk

Technical innovations in the field of predictive and preventive medicine allow for early detection of individual risk factors concerning a constantly increasing number of diseases. This presents health professionals, patients and their relatives with new manifold challenges. From a patient's perspective, to be confronted with a (suspected) increased risk of developing a certain illness does not only mean to correctly understand and appraise the medical ‘objective’ risk prognosis, but also to manage the emotional confrontation with the new, identity-relevant role of being a “person at risk”. While the predicted event lies in the future and may not cause any current strain or suffering, individuals need to make choices and/or take action in the present, with immediate effect and sometimes serious intrusion upon their everyday life and quality of life. This condition and its medical, psychological and social consequences place special demands on individual health literacy (HL). Risk and health information need to be managed by the individual, transferred into the process of (shared) decision-making (SDM) in order to interact effectively with physicians, and integrated into one’s subjective everyday life. The focus of this contribution is therefore at the interface between health risk, health literacy, and communication.

1.2. Health Literacy

Today’s health-society [1] promotes an ideal image of self-effective, proactive patients who are able to make informed decisions successfully managing their own health and/or disease. The concept of health literacy (HL) has become a benchmark for doing health research for people and with people in the aspiration of a healthier society. According to the integrated definition developed by the European Health Literacy Consortium [2,3], “Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course” [2] (p. 3), [4] (p. 4). Based on this definition, risk related HL can be considered as the ability to access and understand information on risk factors for health, derive their meaning, interpret and evaluate this information and to make informed decisions with regards to risk factors for health [2].

Despite the ubiquitous presence of HL, there is a fundamental lack of consensus about the definition, the conceptualisation, and the scope of the term [5]. For the purpose of this contribution, we are drawing on a more comprehensive, resource-oriented approach [6]; following Samerski, we conceive of HL as a situational, multidimensional, and dynamic process, including a variety of sources and forms of knowledge, which is co-produced in social relations [7]. In this light, HL can be considered as being closely interwoven with processes of shared decision making (SDM) concerning medical interventions. For example, Smith et al. [8] found that people with higher health competence perceived decision-making as a joint negotiation process, which they could actively shape, while persons with lower levels of HL appeared to engage in the decision-making process less autonomously; rather than actively participating, they were more likely to accept the doctor’s recommendation. At the same time, subjective HL and the involvement in SDM process have a positive impact on the satisfaction with medical care, the compliance and the success of medical interventions [9]. HL therefore plays an essential role in the extent to which people are involved in decisions about medical interventions and thus how satisfied they are with medical treatment. There is hence a widespread demand of promoting HL in terms of involving patients more actively in decision-making in the context of medical consultations [8–12].

1.3. The Value of Communication

As much as patients are facing challenges of navigating through complex information upon anticipated health conditions, risks and chances of predictive diagnosis and disease prevention, healthcare professionals are expected to provide them with full and comprehensive information about individual disease risks and preventive options, ensuring an environment where there is enough time, communication and empathy to mutually find individual-sensitive solutions. There is a shift in medical consultation models from the traditional, paternalistic patient-physician-relationship, where doctors make recommendations and patients give their consent, towards the model of SDM, meaning the exchange of information and preferences about diagnostic and therapeutic procedures between patient and physician [13]. There is also an ethical claim towards healthcare professionals with respect to risk-adjusted patient-information and preventive decisions: While every medical intervention is per se an act of bodily harm and only legal when informed consent is given by the patient, interventions in (still) healthy persons for the sake of pre-clinical measures and preventive treatment require special accuracy and comprehensibility of information provided by the physician [14]. Ishikawa & Kiuchi [15] almost ten years ago noted with respect to the role of HL in health communication that the concept of HL should be examined not only as an individual set of skills but also "in terms of the interactional processes between individuals and their health and social environment" [15] (p. 1). We believe that by now this approach remained highly underrepresented in the research on HL and are convinced that it may be crucial not only to better understand the interrelation between individual and organisational HL [16] (especially in context of risk), but also for the development of tools, instruments and interventions which can lead to an improved HL on an individual and a social level. In consequence, when striving for a bottom-up approach[1] to HL in "persons at risk", attention needs to be directed to the communicative character of the concept, situating it within the theoretical framework of SDM and health communication. Our approach is informed by a perspective on the interactional dynamics and the power relations that are shaping a communication process and its outcomes. In particular, Habermas' theory of communicative action is considered as fruitful for understanding how HL is co-constructed in healthcare settings, and as a framework for encouraging critical health literacy. This theory proposes claims of validity for judicious communication and mutual understanding, based on equal opportunities concerning the initiation of and participation in dialogue, and contributing to arguments and interpretations. Furthermore, it allows for insight into the individual's lifeworld without neglecting the organisational context, emphasising the interrelation between both. This concept, including its link to (critical) HL, will be elucidated in more detail in the discussion of our findings.

1.4. Aims and Research Questions

The overarching goal of this contribution is to approach HL in its interactional dimension. Employing a health sciences and an ethnographic research perspective, we aim at providing a new bottom-up definitional approach to the concept of HL in the context of health risk, with an emphasis on critical HL. The leading questions of the research project are: (1) How is a person's HL interrelated with the condition of 'being at risk'? (2) What kind of HL do people need in order to manage their health risks (from a bottom-up perspective)? (3) How can HL be promoted in order to support individuals in the process of SDM and of transferring medical risk information into their lifeworld? The aim is not only to enrich the body of research on the theoretical and conceptual underpinnings of HL [17–19] and to contribute to the understanding of HL in the context of risk, but also to provide an empirical foundation for the development of interventions for communication about risk in healthcare settings [15,20], hereby improving HL both on an individual and on an organisational level.

2. Materials and Methods

This qualitative study is part of the project Health Literacy of Persons at Risk – From Information to Action (RisKomp) which investigated the role of HL in persons with an increased risk of developing a disease in one of four exemplary clinical fields (Alzheimer's dementia (AD), familial breast and ovarian cancer (FBOC), coronary heart disease (CHD) and psychosis (PSY)). The choice of these exemplary clinical fields was based on the fact that they allowed a focus on disease patterns with epidemiological relevance in oncology, neurology, cardiology and psychiatry, and thus the exploration of risk perception and HL relevant factors in the field of mental as well as physical disease. By considering diseases with a diverse definition of risk factors and different methods of creating risk profiles (including symptom

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[1] When using the term bottom-up approach in this article, we refer to the attempt to take the perspective of those being studied (the so-called persons at risk) without imposing specialist-driven definitions of health, risk, and HL (top-down approach). Instead of empirically testing existing pre-defined scientific concepts, we put the emphasis on health, risk and HL as understood and enacted by our interviewees.

assessment as well as biomarker and genetic testing), it was possible to include diverse risk patterns in the analyses. A further gain of knowledge was made possible by the spectrum of prevention opportunities and therapeutic approaches, which can either prevent the onset or have a positive effect on the course of a disease. The intervention options concerning the four indication areas range from surgical or medicinal, psychotherapeutic and educational, to no effective medical prevention option so far in regard to Alzheimer's dementia. This allows taking into account strategical deliberations of persons at risk; depending on health-related future scenarios they were confronted with in the course of predictive procedures. The systematic reviews conducted in the first phase of the project provide an overview of the research landscape and current empirical evidence concerning the role of HL with respect to an increased risk in each of the four clinical fields; in addition, they revealed open questions and directions for future research [21–23][2].

The study was planned and conducted in close collaboration with partners in the cooperating specialist centres at the University Hospital Cologne (Appendix A)[3]. Ethics approval was obtained in March 2018 (registration number 18-014) by the Medical Faculty of the University of Cologne.[4]

2.1. Sampling and Recruiting Procedure

For the recruitment of interview candidates, indication specific inclusion and exclusion criteria (Appendix B) were defined in cooperation with the specialist centres for genetic testing or preclinical diagnosis of the University Hospital of Cologne. In a first step, for each clinical field, risk profiles were determined based on current medical evidence (e.g., a particular type of genetic risk or a combination of genetic, physiological, and behavioural risk factors). The aim of this purposive sampling strategy was to enclose a maximum variety of risk manifestations for each clinical field [24]. According to the in- and exclusion criteria, the clinical staff started recruiting the individual participants based on convenience sampling. There is no consensus about the ideal sample size [25]; while it is often necessary to specify a certain number of interviews for ethics approval and funding calculation, the inclusion of ten participants per clinical field was envisaged (40 in total). This number was based on the project aim, the research question, the chosen study design, as well as the available personal and institutional resources.

The collaborating clinics supported us in recruiting participants by pre-screening their patients' profiles with regard to the in- and exclusion criteria, by handing out brief information about the research project to the potential participants, by imparting their contacts to the project team, and by providing facilities for the interviews. In the field of coronary heart disease, in addition to cooperating with teaching practices of the University Hospital Cologne, online recruitment strategies, social media, public displays as well as the contacting of support-groups and relevant organisations were used as recruitment strategies. The clinical staff arranged the first contact with potential participants; all further steps like providing detailed study information, arranging the interview appointment, conducting the interview, and any further communication with the participants was at the authors' responsibility.

2.2. Data Collection

To answer the research questions, we chose a qualitative research design which incorporates three pools of data: (1) narrative interviews on risk and health, (2) body sketches visualising embodied

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[2] The systematic review in the field of familial breast and ovarian cancer is under revision and will be published in 2020.

[3] The collaborating partners were involved in the different phases of the project as follows: sampling and recruiting (clinical staff and the authors), data collection in terms of conducting interviews and taking field notes (LH, ML and SJ), data analysis for each clinical field (LH, ML and SJ), and interpretative analysis across the four clinical fields (LH, ML and SJ).

[4] Before the interview, all potential study participants were provided with information concerning the aims, methods (including details on the interview procedure, possible harms and benefits, and the continuing opportunity to withdraw from study participation), the exploitation of the research results, and data protection. At the outset of the interview, all participants signed a written consent form.

perceptions of risk and illness, and (3) ethnographic data based on notes and memos concerning reflexivity and the research relationship, created before, during and after the interview.

2.2.1. Narrative Interviews

The narrative interview, chosen to be a main source of data collection in this research project, is a methodology of qualitative social research to gain insights into the interviewees' personal experiences, feelings and subjective relevancies in a context of interest. The idea of the narrative interview is to let the interviewees tell their "stories" and herewith communicate their perspective on a subject without narrowing the course of information by giving a direction of conversation with a standardised interview guide [26]. Narrative interviews were deemed suitable for this project since they allow for a bottom-up approach to concepts such as risk and HL. Letting these be defined by the persons' individual perceptions, appraisals, and preferences, narratives can inform the development of theory which is grounded in empirical data. Being interested in HL relevant factors from the perspective of persons at risk, narrative interviews using a flexible topic-guide were the instrument of choice. This approach follows the principle of narrative interviews, starting the conversation with an open introductory question, but sharpening its focus by context-specific in-depth questions (incorporated in the topic guide), pre-defined by the researcher alongside the subject of interest [27]. The interviews started with a question about the first confrontation with being at risk of developing a certain disease[5] [28]. With reference to the interviewees' narratives, in-depth questions were asked on access, understanding, appraisal and application of risk-related health information. The interviews were concluded when no new themes or stories were raised, and upon the researcher's explicit invitation to think of any further potentially relevant issues that the interviewee may wish to describe.

The interviews were audio-recorded with the participants' given consent. The audio material was transcribed verbatim, and transcripts served the text-based analysis of the interviews using MAXQDA 2018 [29]. In addition, sociodemographic questionnaires were included into data analysis that had been handed out to and filled in by participants before the interviews.

2.2.2. Embodied Perceptions of Risk and Illness

At the end of each interview, participants were asked to perform a body-mapping exercise. A sheet of paper showing an empty body sketch was given to participants, who were subsequently asked to depict their feelings about being at risk of developing a disease. Interviewees had the opportunity to comment on their drawings if they felt the needed to do so. The method of body-mapping is an approach with which insights in the individual's embodied realities can be gained, and is used in health sciences [30,31]. Body-mapping allows the non-verbal and creative expression of perceptions, personal feelings and experiences and is therefore suitable for the inductive, bottom-up approach aimed at in this study.[6]

2.2.3. Ethnographic Data Concerning the Research-Relationship

During the interviews, the researchers took field notes concerning content, non-verbal communication, atmosphere and their own experiences and feelings during the interviews using a self-reflection tool developed for the purpose of this study (notes and memos). The documentation and reflection of one's own feelings and observations during and after interviews is a common practice to make the researchers' subjectivity comprehensible and transparent, which is a

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[5] More detailed information on strategies to minimise potential distress for participants, including a reflection on methodological and ethical issues in qualitative research on health risks, can be found in [28].

[6] An appropriate description of the body-maps would be beyond the scope of this article. To avoid an oversimplified presentation, we will therefore refrain from providing examples. The in-depth analysis of the body-maps and their role in the process of theory generation will be thematised in a separate article.

key quality criterion in qualitative social research [32,33]. The notes and memos were included in the data analysis and methodical reflection of the research process.

2.3. Data Analysis

The analysis process of this study is embedded in the overarching approach of the Reflexive Grounded-Theory-Methodology [34], and mirrors an iterative process of three analytical steps: (1) analysis of data (narratives, body-maps and ethnographic data) for each clinical field separately, using a field-specific coding system; (2) interpretative analysis of the findings in all four clinical fields, developing a new integrated coding system, and (3) interdisciplinary data validation and cross-check analysis.

2.3.1. Analysis of the Narratives, Body-Maps and Ethnographic Data for Each Clinical Field Using a Field-specific Coding System

In this first analytical step, data in each clinical field were analysed separately by different team members in an iterative process parallel to conducting subsequent interviews. The goal was to identify categories that are specific to the risk of disease in the respective clinical field, avoiding direct comparisons between data in the process of collection and first analysis. With the exception of CHD, thematic saturation[7] [35,36] was reached before completing analysis for all envisaged (n = 10) interviews in each clinical field; i.e., the main categories remained stable after having analysed approximately six to seven data sets in the respective clinical field, even when including further interviews in the analysis. During the process of open coding, we created a coding system embracing the different data types (narratives (verbal), body maps (visual), and field notes (reflexive)), which provided insights into different emic interpretations of risk, health and HL. Furthermore, through the integration of field notes into the analysis it was possible to address the question of researchers' subjectivity and make it as visible as possible in the analytical process. In the process of axial and selective coding, we searched for interconnections with the concept of HL, both describing it from the patients' perspective and relating it to existing definitions of the concept from the literature. Through this triangulation of methodology and theory [37], we aimed to emphasise the ethnographic, bottom-up character of the research.

2.3.2. Interpretative Analysis of the Findings of All Four Clinical Fields, By Developing a New Integrated Coding System

In the second stage of analysis, we conducted an interpretative analysis across coding systems, integrating the codes of all four clinical fields. Due to the restricted number of interviews in the field of CHD, interpretation was considered with reservation. Both indication-specific and cross-indication findings regarding HL-relevant factors in persons with an increased risk of disease, were compared and discussed within the research team, taking into consideration different perspectives from our disciplinary backgrounds (ethnology, psychology, and health sciences). In this way, we were able to identify categories and relations relevant for all four fields as well as those themes that are specific for each clinical field. For the purpose of this article, we created an overarching category system (Figure 1, Section 3.2) which emerged during the analysis across the clinical fields based on the research questions stated above, and the previously gained in-depth insights in the different fields. Through this approach, decision making processes of people with an increased disease risk regarding the use of early diagnostic procedures and preventive interventions can be reconstructed. This allows for reflecting on conducive models of risk communication in connection with health behaviour and contributes to the theoretical foundation of the concept of HL.

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[7] 'Saturation' can be defined from different perspectives and on diverse levels of research [35,36]; in line with our methodological approach, we refer to the model of 'inductive thematic saturation' [35] which relates to the emergence of new codes or themes during data analysis.

2.3.3. Interdisciplinary Data Validation and Cross-Check Analysis

In the final analytical phase, we aimed at researcher, methodological and theory triangulation, and interpreted and validated the interpretative analysis performed in the second analytical step. For this purpose, we organised interdisciplinary researcher discussions in order to relate the concepts which arose from the empirical data to existing theoretical frameworks in different academic fields, and to test the applicability of the developed theoretical considerations across the four clinical fields.

3. Results

In the following, we will shortly introduce the database of the research project, and present the central findings of our study along the structure of the main categories and sub-categories that we identified during the interpretative analysis.

3.1. Database

The interviews were conducted between April 2018 and August 2019. In total, 34 out of the envisaged 40 interviews were completed. During one interview in the AD group, it turned out that at the time of the study, the respondent already had dementia (exclusion criterion). Therefore, 33 interviews were included in the data analysis (a detailed presentation of the participants' characteristics is provided in Appendix C). In the area of CHD, despite various recruitment strategies during the period of data collection, no more than three persons could be recruited to participate in the research project (Table 1). (The recruiting strategy and possible reasons for the low response rate compared to the other clinical fields will be methodologically reflected in the further course of the evaluations).

Table 1. Interviews conducted and included in the data analysis.

	FBOC	AD	CHD	PSY	In Total
Planned	10	10	10	10	40
Conducted	10	11	3	10	34
Included	10	10	3	10	33

Audio material of approximately 34 h, 1036 pages of transcripts, 33 questionnaires and 31 body-maps, plus the researchers' memo material constituted the data sources used in the data analysis process (Appendix D).

3.2. Main Categories

Hereinafter, our findings concerning HL-relevant factors for people at risk of developing a disease, and HL-related aspects in order to manage these risks, will be presented. The results focus on the respondents' subjective risk and disease theories, as well as on their analytical-reflexive and emotional-intuitive interpretation systems. We identified three central categories which refer to key situations of risk perception, the processing and understanding of disease risk, and risk-related agency of "persons at risk" (Figure 1).

Figure 1. Central categories of dealing with disease risk: key situation, risk understanding, and agency.

3.2.1. Key Situations

In the context of this study, key situations describe a distinct moment or an extended period of the ideational realisation of one's risk. This is determined by a person's biographical background, intuition, and degree of self-reflection. Whether a person is confronted with the risk of developing a disease for the first time or has been confronted with the idea of risk directly or indirectly for years, has an influence on how the risk is dealt with, and on the decision-making processes regarding early diagnostic or preventive measures. In the following, features of key situations identified in the interviewees' narratives will be described. The identified key situations can be differentiated along the process of being confronted with risk, in terms of the emergence of a risk feeling, the time of cognisance of risk, and the impact of key situations.

Genesis

Genesis describes the development that gave the initial impetus for dealing with the concept of risk, and ultimately participating in early diagnostic procedures. Respondents describe an omnipresent risk idea or an intuitive risk perception over a longer period of time to be the reason for the participation in early diagnostic procedures as a form of active engagement with their own health-related future:

> "That's a little strange because, um … that was for me, well breast cancer has always been an issue for me." (FBOCP06)

> "Yeah, I kind of want to know what that is and why. [...] Just to have the certainty." (ADP08)

> "And it's nothing that has uh just been there for three months, it has always been there. Well, it didn't just appear like three months ago, it has always been there." (PSYP10)

Time of Cognisance

The time of cognisance means the moment or period of time of risk confrontation in which participants became aware of their risk. According to interviewees' descriptions, a moment of confrontation in the sense of a sudden awareness of a risk can be caused by biographical upheavals (relocations, life stage changes, crises) or chance findings during routine examinations. Dealing with disease risk over a longer period of time can be the case due to disease experiences in the family or the observation of symptoms that people may associate with the development of diseases and interpret them as a potential precursor (forgetfulness, changes in perception, cardiovascular complaints): "Sometimes I don't have any problems at all and sometimes I think 'It can't be true that you don't remember this anymore!'." (ADP07).

Facing an increased disease risk, whether in a moment of confrontation or over a period of becoming aware, entails a transition or a turning point in the lives of the participants of this study, with characteristic consequences for their identity formation, lifestyle or future perspectives. The interviewees' narratives contain detailed episodic accounts of the situations or periods of becoming aware and inescapably realising that 'something is wrong'.

> "Um, and then, as really the most relevant moment was when I was at the North Cape and the big turquoise wide sea was in front of me, the people around me were all happy, there were some plants around me you can't find anywhere else, and I just didn't feel anything." (PSYP01)

> "I was still young and thin and thought: 'How could that be, diabetes type two, you get that at seventy or eighty or so and if you get it before then, it's because you're a rather chubby person!' I was really shocked. Because I expected everything, but not that I would become diabetic at the age of fifty or in my early fifties." (CHDP01)

Impact

Respondents described key situations to have an existential impact on their considerations and planning with relevance for their life course, their identity, and their family planning: "The consequence of this, if I think about my husband and myself, would be family planning." (FBOCP10), their professional context: "I already told my superior to consider me as a risk factor" (ADP04) or their view on future life in general: "There are days where I only look at the black side of my future." (ADP07).

The impact of key situations on people's perceptions or actions can be of a positive and motivational nature: "I want to stay healthy you know? So living healthily is my contribution to not getting high blood pressure." (CHDP03). At the same time, key situations can have a negative-destructive impact: "All I feel is fear of getting dementia. [. . .] It is in every cell." (ADP01).

This is of central importance with respect to patient information and risk communication. Consultation in the context of early diagnostic counselling and intervention planning can be decisive in terms of the extent to which people who seek advice are motivated and enabled to make health-promoting decisions and actively shape their health development wherever possible.

Key situations can also provide information on peoples' preferences, skills, and strategies in researching and selecting risk-related health information. Whether, for example, they have been informing themselves about a possible risk of illness for a longer period of time or whether they do not yet know or have not sought any information on the subject at all, sheds light on the scope and the content of information needed. This provides a starting point for medical consultation.

The identification of key situations can also mean orientation for individuals' lived realities, their biographical experiences, and their socio-cultural embedding of the risk understanding. These background circumstances are pivotal in terms of people's needs concerning health-related information and decisions.

The available data offer an opportunity to define types of key situations. A typology of key situations with respect to their emergence or time of cognisance (e.g., sudden or foreseeable) and their impact (e.g., shock or confirmation), can serve as an orientation framework in the early diagnostics of risk and preventive praxis, helping professionals to provide risk information based on individual needs.

3.2.2. Risk Understanding

The understanding of risk comprises aspects of subjective risk definition and interpretation, as well as the individual's relative meaning of a disease risk. The following issues were identified with respect to the understanding of risk.

Definition – Describing Risk

People have individual definitional concepts of a disease risk. 'Definition' in this context refers to metaphors and descriptions participants use to name their risk. People, for instance, describe their risk as a "time bomb" (ADP09), a "tattoo" (PSYP10) or a "bookmark" (PSYP10) and thereby reveal risk to be experienced as something threatening, stigmatising or permanent. Defining one's personal risk means naming it on the one hand; on the other hand, naming it by using metaphorical terms also means applying interpretational concepts to it. The definition and interpretation of risk are therefore closely interwoven and determined by personal disease conceptions. Threat rhetoric used by interviewees with regard to their disease expectations show that experience-based disease images, which for example are associated with decay, hopelessness, strain on relatives or the loss of the social role and one's own identity, pre-set a definitional framework: "I would like to see my daughter grow up and be an adequate companion for her and not a […] senile one." (ADP03). The metaphorical description of risk perception and disease conceptions emerging in the context of the body maps, both in visual and in verbal form, provide insightful information about risk-related perceptions or visions of one's own state of health. Definitional concepts and interpretations of disease risk are crucial in the process of meaning-making [38] concerning potential future health scenarios.

Interpretation – Appraising Risk

According to the analysis of the interviews in our study, the appraisal of risk, as illustrated by the following exemplary quotations, is largely determined by personal conceptions of a disease, which in turn are influenced by self-inflicted or externally-intrigued experiences of illness. People who have already experienced the course of a disease, for example by caring for a relative, project these experiences onto themselves and define their own future state of health accordingly: "I know lots of people with dementia in my environment. […] Seeing my friends' parents. That's really bad you know." (ADP05) or "I don't want not to be pretty anymore. […] I have seen my cousin dying of cancer, she looked so ugly. That was really bad." (FBOCP05).

Risk knowledge in the present about an anticipated state of health in the future can influence the perceived quality of life. Thus, the boundaries between being healthy and being ill already are blurred by the imaginary confrontation with a disease risk before the actual occurrence or onset of a possible illness. Perceived symptoms, for instance, can entail a disease experience even before the actual manifestation of a condition: "I have all the symptoms!" (ADP01). This influences everyday life and lifestyle: "This fear that they might say 'Ok, there is something.' keeps me getting these panic attacks." (FBOCP02) or "I definitely try my best to live more relaxed, and not to let it get any worse." (PSYP05).

"Healthy" and "sick" are thus redefined and persons at risk are confronted with identity-relevant changes. HL of persons with an increased risk of illness - their resources and motives to deal with and apply risk-related health information - depends on their ability to integrate the risk status into their own reality and to accept or actively reject it as part of their identity.

In the individuals' perceptions, the perceived risk prevails over the actual (statistical) probability score: "And in the end we are people, not statistics." (FBOCP09). For example, the results of early diagnostic examinations may contradict the feelings of those seeking advice: "I was always, um, totally irritated because of these test results, I have to admit. Because they didn't reflect at all what I am feeling for myself." (ADP05). The consequence can be that an existing risk is not perceived as such: „Well, I don't know. I have been told that I am at risk, so to say. But yeah. That's all." (PSYP02). In this case, people face the conflict of making decisions about a situation of which integration into their lifeworld does not correspond to their own perceptions.

Percentages given to respondents were interpreted subjectively. Risks can be perceived as an omnipresent threat even with a low numerical probability of illness. While early risk detection procedures for some persons can imply the positive effect of an "early warning system" (which will be described in more detail in the following), for others these do not convey a sense of security if they pervasively continue to feel that they are facing a health threat despite the “all-clear signal”. For example, respondents stated that they did not feel any sense of security, even though the result of their predictive examinations did not reveal an increased risk of developing a disease: “I mean, it was a fact that there was something a way it was not supposed to be.” (ADP05). So, the emotional evaluation outweighs the logical interpretation of percentages and factual findings.

Entanglements

In addition to such emotional-intuitive interpretation systems, the analytical-reflective approach is of relevance when dealing with the probability of illness (consistent with the model by Slovic et al. [39] on the emotional and analytical handling of risk). The respondents’ statements on the subjectively perceived relativity of risk refer to risk entanglements as well as to vague versus concrete risk conceptions.

For example, the disease risk that respondents were undergoing early diagnostic procedures for, was repeatedly named in connection with parallel existing diseases or disease risks: “Being overweight is part of my biography. I am overweight now [. . .] and I have been overweight as a kid or as a teenager.” (CHDP03). Risks are therefore not perceived and processed as isolated entities but understood as interdependencies with other risks: “It could be that my depression has affected my cognitive condition, couldn’t it?” (ADP04) or “Sure there is a risk when you smoke and drink alcohol.” (FBOCP01).

When dealing with a certain disease risk, persons reflect their own (prospective) health as the totality of various (risk) factors. Reflection in the sense of critical HL [40] goes beyond the differentiated examination of health-related risk information and includes an examination of one’s own lifeworld in terms of values, preferences, habitualisation, and social circumstances. As a practical implication for early diagnostic consultations and treatment, these findings can inform starting points for health-promoting or preventive measures.

Vague versus concrete risk conceptions determine to what extent people adopt a “diagnosed” risk probability and include it in their consideration processes and actions. The perceived degree of abstraction of both the risk and the respective image of disease plays a role here. Our data allow the assumption that risk developments and disease progressions with psychological or mental effects are likely to be experienced as more difficult to “grasp” than risk prediction of diseases with physical consequences, the development of which can be – according to respondents’ appraisal – specified more precisely by means of biomedical parameters: “Subjective cognitive disorder, my God. You have your aches and pains and that’s just one of them.” (ADP03) or “I’m not saying that everybody has mental issues but in some way [. . .] other people do struggle with their everyday life, too.” (PSYP01).

Warning System

Irrespective of the degree of abstraction of the risk, people who participate in early diagnostic procedures actively deal with their risk. In this context, risk prediction is interpreted as a kind of early warning system and as a resource in the informed handling of one’s own health. Respondents describe that the medical prediction of their likelihood of disease gives them a feeling of clarity and therefore the opportunity for active prevention – in terms of medical interventions, organisational preparations or lifestyle changes. The last quotation also underscores the blurring between ‘risk’ and ‘disease’ in the interviewees’ accounts.

> “That’s why I’m glad I was able to deal with my problems now. [...] And I’m just glad that this bang fortunately caused the discernment that I have to let people help me.” (PSYP07)

> “That was just another piece of the puzzle for me. It was absolutely out of question. Either you want to know or you don’t. I already said before I knew for certain: Just take my breast off!” (FBOCP04)

> “We have decided to downsize a little with respect to our living. Age-appropriate. That as well has to do with my dementia.” (ADP06)

Our interviewees’ risk narratives reveal the process of understanding, evaluating and applying risk information. Subjective interpretation patterns and relevance systems are crucial for the interpretation of risk and the resulting motivation to act. This negotiation process can be revealed through the narratives of those seeking advice to meet their needs with regard to medical consultation and treatment.

3.2.3. Agency

The category “Agency” refers to individual autonomy and manageability in view of an increased risk of illness. It comprises emotional, cognitive, and behavioural strategies that our interviewees reported in order to (re)construct their capacity to define their situation, to make choices, and to act independently. This includes aspects of information and knowledge management, the role of attitude and identity in dealing with a health-related risk, individual strategies of action, and the role of health care professionals in risk perception and processing.

Dealing with Information and Knowledge

Respondents name various sources of information they use to get informed about their disease risk, including articles, studies, TV and books. They also mention the Internet and the social environment to be central media for the exchange of experiences or personal opinions and the search for risk- or disease-related information: “And when you read something like this, what do you do nowadays? Google.“ (ADP03) or „I talk to my husband, he is of great help to me.” (FBOCP03). The finding and understanding of health information does not refer to an isolated source of information but to a construct of several sources of information, which people individually choose and evaluate. The information medium therefore goes beyond the medical setting and the doctor-patient communication setting in early diagnostic procedures. According to the respondents, the primary information strategy is to obtain health information by oneself: “I can only recommend to get as much information as possible.” (ADP04). They critically decide where to look for information: “You have to be careful about where you find your information, right?” (FBOCP01), what information they choose for themselves: “I don’t trust my doctors exclusively anymore.” (FBOCP01), and which information they want to or do not want to deal with: „Sometimes you just don’t want to know it in cold print, you know?” (ADP07). Information seeking and evaluation strategies depend on the individual’s systems of experience and relevance.

Attitude and Identity

In terms of attitude and identity, personal competences such as interest, motivation, self-reflection and self-efficacy are essential prerequisites for the way people deal with information about and the personal exposition to health risk. Participation in predictive procedures, for example, is described as self-initiative based on self-observation and self-reflection. With the decision for or against information, examinations, study participation or reporting of findings, a competence for one’s own needs becomes visible, which has to be included and taken into account during counselling.

Of equal importance for attitude and identity in dealing with a disease risk is the social environment. Persons within the social network – family, partners, and friends – directly or indirectly influence decision-making processes with regard to early diagnostic procedures as well as the negotiation processes regarding therapeutic measures. Direct influence exists, for example, when relatives actively encourage participation in diagnostic testing: “Well I have to say, my oldest daughter was the one who told me to see a doctor.” (ADP07). Indirectly, a feeling of responsibility towards relatives may for instance be decisive for a person’s step towards medical risk prediction: “I have three children. I think about them, I don’t really think about me.” (FBOCP02).

While identity and attitudes determine how health risks are dealt with, they can also be influenced by the way risk is conceptualised.

"I am a risk factor." (ADP05)

"And then you go like: 'Oh shit – this is like a tattoo!' That's gonna stay for now." (PSYP10)

For the promotion of health-literate action in dealing with disease risk, this finding shows that factors such as intrinsic and extrinsic motivation as well as input from the social environment deserve to be taken into account in medical consultations.

Strategies

In dealing with a disease risk, our interviewees reported having developed personal strategies. These include, for example, subjective explanatory models and measures to maintain or improve the subjective quality of life. As elaborated further below, explanatory models are both a strategy to process the origin and development of risk within people's own logical system. At the same time, these models are the starting point for the development of strategies for dealing with a disease risk, which involves the acceptance of a "new" reality and the assumption of the risk status. Health-oriented decisions and lifestyle adjustments can be the result.

With reference to our interviewees, explanatory models of risk were individual and biographical. When negotiating one's own risk, not only information from outside is taken into account, but also theories of justification which are constructed by the individuals themselves. In this way, they explain their own risk by stress and psychological strain due to for example overwork in everyday life: "I think I have been permanently overstrained all my life." (CHDP02), concern for relatives and family: „I have a ten year old daughter. What will happen to her?" (ADP02) or disease burden: "Well, there are two areas that need to be worked on. There is my depression, and these signs of psychosis." (PSYP01).

Strategies described by respondents regarding the management of disease risk relate to actively influencing one's own health and maintaining quality of life by leading a health-promoting lifestyle: "I do my best to live a healthy lifestyle, eat healthy food, do sports." (CHDP03) and by continuing everyday life and one's social role: "Continuing everyday routines, that's what is important." (ADP05). Following on from the central explanatory model of stress as the cause of an existing disease risk, stress avoidance or stress reduction are central strategies, universal to respondents in all clinical areas addressed in this study.

The orientation of strategies is decisively influenced by the therapeutic interventions and preventive options available with regard to the prevention of the onset of a disease or the positive influence on the course of a disease. For three of four indications included in this study (CHD, FBOC, and PSY), these strategies range from surgical interventions and drug therapies to psychotherapeutic and educational approaches. For AD, to date, no effective prevention or cure exists, even at an early stage of risk prediction. However, knowing about the risk can offer the opportunity to make provisions in terms of organisational and existential matters: "Everything is prepared. [. . .] If I got Alzheimer's dementia tomorrow, I would have everything organised." (ADP03).

Role of Health Care Professionals

The handling of information about one's own disease risk and the development of strategies for action are thus decisively related to biographical and personality-related relevance systems, information needs and explanatory models.

Do the data also provide insights into the role of consulting physicians in connection with risk perception, processing and risk-adjusted decision-making? The respondents' comments on the consultation on risk prediction and possible preventive treatment they had experienced ranged from statements of complete satisfaction and feeling well-informed, to the condition of feeling as clueless as before the consultation: "I feel totally well advised." (FBOC08) or "I know just as much as I did before." (ADP08).

Patients critically reflect on the counselling situation and the information content, and compare it with their own needs. The role assignment to health care professionals in dealing with a health risk is also negotiated by patients: "I kept asking what I could do about it but she never really gave me any answers." (ADP08)

A central expectation towards health care professionals in this context is their empathy and understanding with regard to the individual situation of those seeking advice: "A doctor, even if he can't help, a doctor should be a person who is able to listen." (FBOCP05). There is also a desire for communication "at eye level". The power-relation in patient-doctor communication is addressed in various contexts and forms an important category, as it can adversely affect the use of consultation or participation in decision-making processes.

> "But on the other hand, it's actually very important, well it happened now already, um, twice, that something important just showed up in the results .., about which my doctor didn't talk to me." (ADP05)

> "I just don't trust doctors anymore. Oh God, I have experienced so much that I prefer using my own head. [...] Things you experience are not always that enjoyable, you know?" (FBOCP01)

With reference to power relations and participatory decision-making in risk diagnostic counselling and preventive treatment, people seeking advice describe how they feel restricted in their freedom to act. For example, they felt that their choices were influenced by strategic rhetoric they experienced in conversations with their doctors: "It would be better if there were people who helped you in your interest, without giving you the feeling of pushing you towards something they want." (FBOCP01). These findings emphasise the relevance of asymmetric power structures between patients and health care professionals, due to an imbalance in medical knowledge and expertise, for SDM in the course of medical consultations.

Positive experiences with medical consultations in the predictive field, however, can enable relationships of trust with medical services in general, and with practitioners in particular:

> "A trusted relationship with my doctor is essential to me. Now I ended up with a doctor I don't have any connection to. And in that case ... well, with her, I would rather not talk about sensitive stuff." (CHDP03)

> "Where it actually kicked in for me were my therapy sessions. [...] Because of them, I was able to see things more clearly." (PSYP10)

These results can contribute to the expansion of the concept of HL by including essential aspects that are relevant for the promotion of HL, especially in the setting of risk prediction. The data emphasise the self-reflected way of persons at risk in dealing with risk information, their own biography and identity in the context of risk, personal definitional concepts of risk and illness, and their perception of risk diagnostic consultations. These results serve as starting points to enable health literate decision-making and action-taking in medical risk context. The reflection of key situations in recognising risk, processes of understanding risk and the negotiation of strategies in dealing with risk are aspects that deserve consideration with respect to identity formation, and with regard to communication strategies in the context of SDM in medical consultations and beyond. Practical implications, both for the expansion of the concept of HL and for early diagnostic consultation practice, will be discussed in the following.

4. Discussion

The data of our study provide unique insight into the tension fields between HL, risk, and predictive medicine by adopting the perspective of our interviewees – the so-called "persons at risk". In this way, our findings can make an important contribution to research on HL, and hereby enrich its theoretical anchoring.

Our findings raise exciting questions about (1) the definition of HL from a bottom-up perspective, (2) the co-construction of HL within the communication process, paying particular attention to the effects of strategic/persuasive communication on SDM, and (3) HL instruments that may have a positive impact on both health system and lifeworld in the context of risk. In the following, we will illuminate each of these fields, grounded in both theoretical and empirical considerations.

4.1. Defining HL from a Bottom-Up Perspective: Jumping the Frame of Dealing with Health Information and Opening up a Space for a More Holistic Approach

Our findings support the definition of HL by WHO [2,3] as a complex human competence, which is impacted by different factors. Especially in the context of risk, HL can be described, from the perspective of respective individuals, as a way of balancing between different sources of risk information: the physician or the health system, the Internet and other media, somatic feelings, explanatory models, biographic experiences, and everyday life (in terms of subjective quality of life) which evolve in the context of their individual lifeworlds.

In the preparation phase of our research, we used the integrated model by Sørensen et al. [2] as a template and an orientation framework for the development of our study design and the interview-guide, assuming that HL in the context of risk would follow the same or a similar logic. Nevertheless, after first data emerged and was analysed, we quickly realised that an interdisciplinary and multidimensional theoretical embedding will be needed in order to grasp the great amount of symbols and meanings generated throughout the research process. We needed to situate our findings within the field of the HL research (individual and organisational, critical and relational) but also in the sphere of health communication and SDM as well as social science research. The interplay between risk information, the individual explanatory model of risk, intuition, and the ability to reflect on all three aspects (Figure 2) clearly illustrates the necessity to merge different theoretical approaches. This model depicts the understanding of HL from a bottom-up perspective.

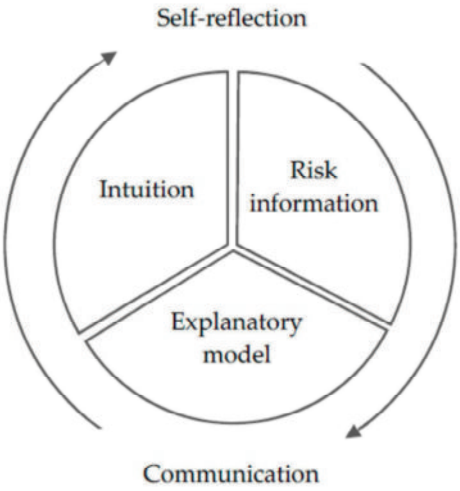

Figure 2. Model of HL in the context of risk– co-construction of risk interpretation and meaning.

On the one hand, this model emphasises the importance of learning more about the patients' explanatory models of sickness [41] and risk as a way to grasp relevant information in the context of their lifeworld. On the other hand, it refers to Slovic's [39] theory on risk mentioned above – risk probabilities as part of the analytical system and intuition as part of the emotional system which both on an equal stance enable individuals to make decisions about risk. Furthermore, the dimension of reflection highlights the importance of different domains of critical HL, as described by Chinn [17]: critical appraisal of information, understanding social determinants of health and collective action. These findings are not pioneering in health research; however, they shed a different light on the field of HL in the context of risk perfectly illustrating the "mismatch between 'biomedical' and 'lifeworld' agenda" [42].

Based on these findings and building on already existing work [7,43,44], we propose a complementary definitional perspective to the concept of HL, employing an ethnographic and health sciences bottom-up approach.

4.2. HL as Communicative Action?

In the process of data analysis, the interaction between lifeworld and system turned out to be central for understanding HL in the context of risk from the interviewees' perspective. For a sound theoretical anchoring of this finding, the philosophical foundations of the theory of communicative action by Jürgen Habermas [45] were considered an appropriate and fruitful background for the theoretical embedding of the empirical data, seeking to bridge action and systems theories. Furthermore, this approach incorporates the notion of power in health communication, which emerged as a central issue when discussing the role of critical HL in the context of predictive and preventive medicine. According to Habermas, actors' coordination of actions based on common norms is not self-evident, but must always first be reached by mutual agreement between the parties involved; the way in which this happens is through linguistic communication.

In the context of HL and risk communication, the existing literature provides insight into the common norms underlying communication or SDM in medical contexts. But what do we know about the way the actors (professionals and patients) coordinate and negotiate their health-related actions?

Categories like self-reflection, agency, interactions (in the context of patients' lives and health system) can be fruitfully used to draw an analogy to the Habermasian tensions between (a) lifeworld and system and (b) communicative and strategic action, and provide an inspiring theoretical framework to contextualise the risk-encounter in terms of HL. In the following, we will relate our findings to the theory of communicative action, arguing that this allows for an additional, practice-related and intervention-oriented approach in operationalising and doing research on HL.

4.2.1. Lifeworld and System

The interviewees' risk narratives play a central role in our empirical findings. On the one hand, we see the personal risk narrative which reveals the social integration of the new status as 'person at risk' within one's own lifeworld. On the other hand, we hear the individuals' interpretations of the professionals' narratives, which provide an insight into the assimilating mechanisms of the health system, giving the 'person at risk' a certain system-relevant role and access to prediction and prevention. Speaking with Habermasian terms, the system is "colonising" the lifeworld labelling a certain statistical probability as risk and attributing to a still healthy person the status of "person at risk". In this sense, we can see HL as communicative action where validity claims about risk are made and negotiated. Therefore, the ability to integrate the systemic knowledge into the individual lifeworld and vice versa is an integral part of HL as a dynamic process in both individuals (including the professionals) and the system. Based on this we are prone to see HL as a communicative action that enables professionals, patients, and their relatives to use the risk consultation for negotiating the lifeworld and system narratives and achieve a social and systemic integration of the condition of 'being at risk'.

In line with the Habermasian theory of communicative action, we therefore believe in the necessity to combine the action- and systems theoretical perspective while doing research on health at risk. Especially in the context of HL, such a theoretical bridge is essential in order to integrate both bottom-up and top-down research perspectives, while addressing the concept and allowing for a holistic approach to health risk and communication.

4.2.2. Communicative and Strategic Action

The Habermasian theory differentiates between two types of rationality – the strategic and the communicative reasoning. Communicative action is oriented towards understanding, consensus and balance; strategic action towards manipulation and personal goal achievement. The interview data also mirror this tension; individuals identified situations in which they felt being persuaded to choose for a certain option of risk prediction or prevention. The empirical data show that individuals describe the communicative action as "communication at eye-level", which harmonises the agendas of both actors – patients and doctors. Individuals also detect and describe in detail consultation situations in which they felt like a victim of strategic action and communication.

In the context of risk communication in predictive medicine, we should address the ethical question of wishful thinking with regard to HL from both patients' and professionals' perspectives – should HL perform a communicative or a strategic role? Our data showed that individuals at risk see HL as a process of communicative action in the context of SDM; it will be particularly interesting to learn more about the perspective of professionals in this context – do they see the goal of the communication in uniting both agendas (in the same sense as SDM), or do they (unconsciously) engage in persuasive rhetoric? Greenhalgh et al. found that:

"Lack of trust, intense pressure of time, mismatch of agendas (biomedical versus lifeworld), firm expectations of a specific outcome (e.g., referral, prescription) and profound power imbalances all promote strategic action (i.e., speech that seeks consciously or unconsciously to manipulate an outcome) rather than communicative action (i.e., sincere efforts to achieve understanding, and reach consensus) by all parties." [42] (p. 1170)

In this sense, we are deeply convinced that the understanding of the concept of critical HL should be expanded with one further aspect or category – the ability to engage in communicative action and to detect and reflect on strategic action in the process of the risk consultation. Communicative action requires symmetry. In the case of health at risk we need to critically review the validity claims of both parties. Carel & Kidd [46] argue that ill persons are particularly vulnerable to *epistemic injustice*, while health professionals are considered to be epistemically privileged, and the structures of the health system encourage this condition of epistemic injustice. We suggest that this concept may be enormously fruitful when discussing HL in the context of risk on both theoretical and practical level, drawing the attention to the ethical dimensions of HL-promotion.

Following this argumentation line, future research needs to ask further questions on the prerequisites for communicative action in the field of predictive medicine, where lack of certainty is omnipresent: Which are the major barriers to HL as communicative action?

4.3. Intervention-Oriented Theory on HL as Communicative Action – Draft and First Ideas

Broadening the definition of HL, emphasising the interaction as the space within which HL is manifested and may be promoted offers a new perspective on the development of instruments for measuring and promoting HL. Based on our findings and the theoretical considerations above, we suggest the following impulses for future research and intervention development.

4.3.1. Interaction as a Target

Based on our empirical findings and their theoretical embedding, we recommend moving the focus on the process of interaction between physicians and patients, not only during the risk consultation itself, but also during preparation and follow-up processing. The results of this study suggest that we should rethink the way of designing HL promotion interventions (especially in the context of risk) which usually aim at contributing to the "accurate understanding" of numbers and statistics. Instead, we should turn our attention also to the consultation encounter itself, enabling patients and professionals to engage in communicative action, detect and disclose strategic communication and reflect on both medical and lifeworld-oriented explanatory models of risk and its consequences.

One possible way to take up the patient's explanatory model on the one hand and encourage him/her to engage in communicative action on the other is to explore the key situation of risk during the consultation process. The nature of the key situation can provide information about the socio-cultural embedding of the individual understanding of risk. The processing of the key situation in the counselling situation can strengthen a person's health competence and support professionals in conveying risk information in a patient-centred manner. Discussing the key situation and the explanatory model of risk behind it can contribute to bridging the space between 'patienthood' and 'physicianhood' [47] (p.352).

4.3.2. (Self-)Reflection as a Tool

One of the key results of the current study is the necessity to add a new, additional dimension to the concept of critical HL in the context of risk – the ability to detect and reflect on strategic communication within the risk-consultation. Furthermore, the competence to integrate the status of being at risk into the individual everyday world and identity, translating medical and systems knowledge into one's lifeworld experience, has turned out to be a central resource for approaching HL from a bottom-up perspective. However, how can both types of competences be promoted in the course of the consultation?

One possible tool is to integrate self-reflection components in the process of providing, receiving and negotiating risk information. In the course of our research, we found that patients' narratives do not only reveal information on their medical risk status, but also on the way they have understood and translated this information into their life-world language. Moreover, their accounts may also provide evidence on the strategies individuals have adopted in order to handle the risk information and its consequences. We believe that integrating these narratives in the risk consultation may lead to an increased patient sovereignty [48], more effective communicative action, and extended HL.

4.3.3. Individual and Organisational HL at Once

Our results show that individuals perceive, define, and analyse the role of the health system in the process of risk negotiation primarily through the lens of their interactions with professionals in terms of communication and treatment. With regard to SDM, our interviewees' experiences of strategic communication by healthcare professionals also underscore the importance of paying attention to prevailing asymmetric power relations in healthcare encounters; 'expert knowledge' concerning risk was perceived as a sole privilege of the professionals' role. In line with other authors, this encouraged us to ask for a more holistic approach to HL promotion on both an individual and an organisational level. For example, Samerski describes individual HL as "a bricolage of different forms of knowledge" [7] (p. 4). Greenhalgh et al. argue that a "failure to play both system and lifeworld roles effectively" [42] (p. 1184) may lead to distorted communication. Carel & Kidd [46] propose a 'phenomenological toolkit' to support symmetry and epistemic justice in encounters between patients and healthcare professionals, and to reconcile the patient's experiential first-person narratives with the 'objective' third-person accounts characteristic of the medical world. We will support and further develop this argumentation line, claiming that 'colonising' individuals' lifeworlds with medical and system-centred risk information is a too narrow interventional concept for HL promotion and we believe that in the doctor-patient relationship, more space should be reserved for communication, and for the patient's lifeworld.

5. Limitations and Reflection

Throughout different stages of the research process, this study faced some challenges and limitations:

5.1. Methods and Setting

Methodologically, the process of theoretical sampling and the definition of the inclusion and exclusion criteria deserve consideration. In this study, only individuals were included who had been attested an "objective" and medical risk (e.g., genetic mutation). Nevertheless, during the analytical process we realised that the perceived "subjective" risk - which is not based on medical factors and statistics, but on lifeworld-knowledge, intuition, and experience – is as important as the "objective" risk. For future research on risk and HL we suggest also including individuals who believe to be "at risk" even if they cannot prove it in terms of medical documentation.

5.2. Recruitment and Sample

By interviewing only people who have participated in early medical diagnosis procedures, the focus of this study is narrowed. In consequence, persons not involved in services of early diagnostics for any reason (e.g., because they do not have access or willingly reject making use of them) are excluded. The findings of this study can therefore not be generalised unrestrictedly to persons 'at risk'. Participants' sociodemographic data showed that the sample of this study was rather homogeneous in terms of educational and social background. Therefore, future research on this subject should incorporate recruitment strategies that ensure a more diverse sampling structure with regard to sociodemographic background and experiences with pre-clinical diagnostics.

5.3. Analysis

This article is based on comparative, interpretative analysis of data from four clinical fields. Contrary to what we expected, we were not able to recruit 10 individuals at risk of developing Coronary Heart Disease, and hence conducted only three interviews. We therefore did not reach thematic saturation [35] in the first analytical step. We were nevertheless able to identify some core themes for this group, relate them to already existing research, and then use the key messages as an orientation framework for interpretative analysis. Our experiences will inform a reflexive, methodological discussion on the criteria of defining individuals "at risk" of developing CHD (currently under preparation).

5.4. Research Environment

Apart from these concrete study limitations, we should pay attention to a more general one, which can be seen as both limitation and challenge – the academic/research environment within which qualitative empirical research on health is being conducted, presented and published. In a medically oriented environment, there is a common sense of doing research in a standardised manner with a linear research process, designed to answer pre-defined hypotheses. A circular research process, defining research questions and using the empirical research to create hypotheses and to generate a theory grounded in data, is still not very common. Researchers hence need to plan additional resources for defending, explaining and legitimising their qualitative exploration-oriented approach within the research environment, and in cooperation with the medical team.

6. Conclusions

In our study, we used a qualitative, open methodological approach to investigate the role of HL among persons confronted with a potentially increased disease risk. We identified three central categories that shape individual HL: key situations of risk awareness, the understanding of disease risk, and risk-related agency. These categories are interrelated and play an important role in the process of making meaning of one's risk, coping with it, and integrating it into one's identity, health-related behaviour, and life plan. There are several implications for clinical practice, theory building, and future research.

In terms of clinical practice and intervention development, our findings are of vital importance with regard to patient information and risk communication. Our interviewees' narratives showed that the process of risk negotiation is characterised by introspection and self-reflection, and is closely connected to individuals' interactions with healthcare professionals. Their rich accounts provide a foundation for the development of practical guidance to support HL in the context of risk in clinical patient-doctor interactions. The way risk is communicated and framed will strongly affect a person's perception of agency in the sense of autonomy and manageability. This includes individual strategies of information management, decision-making, and acting in view of an increased disease risk. These insights emphasise an understanding of HL as a communicative action, and as a co-construction between the individual, the healthcare professional, and the healthcare system. Hence, actively including patients' narratives in risk counselling encounters (e.g., by exploring key situations of a person's confrontation with the respective risk) can be conducive to an effort for more power balance and 'epistemic fairness', and for supporting HL in the context of risk prediction and prevention.

In terms of the theoretical underpinnings of HL and future research directions, the results of our study can contribute to an expanded concept of HL, including essential aspects of relevance for the context of risk prediction. Our findings provide insight into individual manifestations of being health- and risk-literate beyond medical information or statistical skills. The interviewees' risk narratives reveal their very individual journey of understanding, evaluating and applying risk information. We therefore believe that our study will be a valuable complement to the research landscape in terms of theory building and conceptual reflection on the meaning of HL. It can enrich existing work with perspectives on HL grounded in people's narratives and ethnographic data, hereby contributing to the theoretical grounding of the concept. In methodological terms, future studies may benefit from a more extensive consideration of qualitative designs, in particular ethnographic and participatory approaches, in order to allow for a more open, resource-oriented approach to HL. Moreover, the results of our study can serve as a basis for further research on HL as a communicative element between patients or persons in search of advice and medical professionals; and they can offer starting points for communicative action as a means to realise individual and organisational HL.

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Appendix A

Table A1. Institutions involved in the recruitment process.

Familial Breast and Ovarian Cancer: Zentrum Familiärer Brust- und Eierstockkrebs, **Rita Schmutzler und Kerstin Riehm**	**Alzheimer's Disease:** Zentrum für Neurologie und Psychiatrie, Klinik für Psychiatrie und Psychotherapie, **Frank Jessen und Ayda Rostamzadeh**
Coronary Heart Disease: Schwerpunkt Allgemeinmedizin, **August-Wilhelm Bödecker und Jörg Robertz**	**Psychosis:** Früherkennungs-und Therapiezentrum für psychische Krisen, Klinik und Poliklinik für Psychiatrie und Psychotherapie, **Theresa Haidl und Mauro Seves**

Appendix B

Table A2. Inclusion and exclusion criteria in four clinical fields.

Inclusion Criteria	Exclusion Criteria
Coronary Heart Disease Adults (a) with an increased risk of developing coronary heart disease (CHD) or (b) those suffering from clinically manifest CHD (according to the cardiovascular disease risk charts of the European Society of Cardiology [49]). (a) adults without known CHD Age: women > 60 years; men > 50 years Hypertension (blood pressure > 140/95 mmHg) and/or total cholesterol > 200 mg/dl and/or smoking and/or diabetes mellitus (b) adults with known CHD Women and men with known KHK, smoking and/or blood pressure > 140/95 mmHg and/or LDL cholesterol > 100 mg/dl and/or diabetes with HbA1c > 7.5%. Written declaration of consent German language skills that allow the interview conduction	- Age < 35 years - Severe physical disease (except CHD and diabetes mellitus) - Mental illness (e.g., dementia, substance dependence, psychosis)
Psychosis - Adults who fulfill the clinical high-risk criteria for psychosis (basic symptom criteria (SPI-A) and/or the ultra-high risk criteria (SIPS)) - Written declaration of consent - German language skills that allow the interview conduction **Alzheimer's Disease** - Written declaration of consent German language skills that allow the interview conduction **Clinical Criteria for the Diagnosis of an MCI (According to NIA-AA Criteria):** Cognitive impairment (self or foreign medical history reported) Objective impairment in one or more cognitive domains Maintain daily life activities (ATLs) No dementia	- Age < 18 years - Increased risk based only on instruments of self-assessment - Known presence of a traumatic event - Current clinically relevant depressive episode, anxiety symptoms or suicidal tendencies - Dementia Indications of a non-AD neurodegenerative disease such as: Parkinson's disease, Lewy's body dementia, frontotemporal lobar degeneration, very rapid cognitive deterioration within a few weeks or months (classically indicative of a prion disease, neoplasia or metabolic disorder) or brain tumour

Table A2. *Cont.*

Inclusion Criteria	Exclusion Criteria
Clinical Criteria for the Diagnosis of an SCD (According to the Criteria of Jessen et al. 2014): Subjective and persistent (not acute) deterioration of cognitive performance compared to the original starting level Neuropsychological test battery, which is used for MCI or prodromal AD, shows a positive response within the age range, gender- and education-adjusted norm group lying findings	- Current clinically relevant depressive episode (GDS >11), other serious psychiatric disorders or suicidal tendencies - MCI, prodromal AD or dementia - impairments caused by a psychiatric* or neurological disease (excluding AD), somatic disease, medication or substance abuse can be explained * mild subsyndromal depressive symptoms or anxiety symptoms are not considered an exclusion criterion
Familial Breast and Ovarian Cancer - Group 1: Carrier of a BRCA1 or BRCA2 mutation - Group 2: Carrier of a mutation in a moderate risk gene (e.g., CHEK2) - Group 3: No mutation detection in one of the known risk genes, but increased mathematical risk of disease due to own and family anamnesis - Written declaration of consent - German language skills that allow the interview conduction	- Age < 18 years mild cognitive disorders or Alzheimer's dementia - Current clinically relevant depressive episode, anxiety symptoms or suicidal tendencies

Appendix C

Table A3. Sociodemographic sample description per clinical field.

		FBOC (n = 10)	PSY (n = 10)	AD (n = 10)	CHD (n = 3)	TOTAL (n = 33)
Gender	Female	10	4	3	1	18
	Male	-	6	7	2	15
	Other	-	-	-	-	
Age	18–30	1	9	-	-	10
	31–40	5	1	-	-	6
	41–50	3	-	-	1	4
	51–60	-	-	1	1	2
	61–70	-	-	8	1	9
	≥ 71	-	-	1	-	1
Marital Status	Not specified	-	-	1	1	2
	Single	3	9	1	2	15
	Married	6	1	5	-	12
	Widowed	-	-	1	-	1
	Divorced	1	-	2	-	3
	Separated	-	-	-	-	-
Living Conditions	Alone	1	2	2	1	6
	Shared apartment	-	4	-	-	4
	With partner	5	1	5	2	13
	With relative	1	2	2	-	5
	With partner and relative	3	-	1	-	4
	Other	-	-	-	-	-
Cultural Background	German	7	7	9	3	26
	Bi-cultural	2	3	1	-	6
	Other	1	-	-	-	1
Mother Tongue	German	7	8	9	3	27
	Bi-lingual	2	2	1	-	5
	Other	1	-	-	-	1
Education	Abitur [1]	8	8	4	2	22
	Fachhochschulreife [2]	-	-	3	1	4
	Mittlere Reife [3]	2	2	1	-	5
	Polytechnische Oberschule [4]	-	-	-	-	-
	Haupt-/Volksschulabschluss [5]	-	-	2	-	2
	No school certificate	-	-	-	-	-
	Other	-	-	-	-	-
Employment Status	Full-time	5	6	1	-	12
	Part-time	4	-	2	2	8
	In training/study	-	3	-	-	3
	Homemaking	-	-	-	-	-
	Retirement	-	-	5	-	5
	Jobseeker	-	-	1	-	1
	Unemployed	-	-	1	1	2
	Work disability	1	1	-	-	2

FBOC—Familial breast and ovarian cancer. PSY—Psychosis. AD—Alzheimer's disease. CHD—Coronary heart disease. [1] Abitur = Highest degree of German school system, general or subject-specific higher education entrance qualification. [2] Fachhochschulreife = Degree of German school system qualifying for general or subject-specific upper secondary school entrance. [3] Mittlere Reife = Middle degree of German school system qualifying for vocational school or comparable. [4] Polytechnische Oberschule = School form of former German Democratic Republic, comparable to degree of "Mittlere Reife" [5] Haupt-/Volksschulabschluss = Qualification of a general school form of middle education.

Table A4. Sociodemographic sample description per interview partner.

Clinical Field	Sex	Age	Marital Status	Living Conditions	Cultural Background	Mother Tongue	Religious?	Highest School Leaving Certificate	Branch/ Profession-al Activity/ Education	Employment Relationship	Long-Term Med. Treatment	Chronic Disease
FBOCP01	Female	41 to 50	Divorced	With rel.	German	German	No	Abitur ^{1}	Social area	Fulltime	Yes	No
FBOCP02	Female	31 to 40	Unmarried	With partner	German	German	Yes	MR ^{3}	Economics	Part-time	Yes	Yes
FBOCP03	Female	31 to 40	Married	Partner & rel.	Bi-cultural	G. & others	Yes	Abitur ^{1}	Social area	Part-time	No	No
FBOCP04	Female	18 to 30	Unmarried	With partner	German	German	No	Abitur ^{1}	Art & culture	Disabled	No	No
FBOCP05	Female	41 to 50	Married	Alone	Bi-cultural	G. & others	n.a.	Abitur ^{1}	IT	Fulltime	Yes	Yes
FBOCP06	Female	31 to 40	Married	With partner	German	German	Yes	MR ^{3}	Health area	Fulltime	Yes	No
FBOCP07	Female	41 to 50	Married	With partner	German	German	Yes	Abitur ^{1}	Other	Fulltime	Yes	Yes
FBOCP08	Female	51 to 60	Married	Partner & rel.	German	German	Yes	Abitur ^{1}	Health area	Part-time	Yes	Yes
FBOCP09	Female	18 to 30	Unmarried	With partner	Other	Other	Yes	Abitur ^{1}	Health area	Part-time	No	No
FBOCP10	Female	31 to 40	Married	Partner & rel.	German	German	Yes	Abitur ^{1}	Health area	Fulltime	Yes	No
ADP01	Female	61 to 70	Divorced	Alone	German	German	Yes	FH-Reife ^{2}	Health area	In pension	Yes	Yes
ADP02	Female	61 to 70	Married	With partner	German	German	No	Abitur ^{1}	Social area	In pension	Yes	Yes
ADP03	Male	61 to 70	Married	Alone	Other	Other	No	Abitur ^{1}	Other	In pension	Yes	Yes
ADP04	Male	61 to 70	Married	Partner & rel.	German	German	Yes	FH-Reife ^{2}	Health area	Fulltime	Yes	Yes
ADP05	Female	61 to 70	n.a.	With partner	German	German	No	MR	Admin.	Part-time	Yes	Yes
ADP06	Male	61 to 70	Married	With partner	German	German	Yes	Abitur ^{1}	Science	In pension	No	Yes
ADP07	Female	61 to 70	Widowed	With partner	German	German	Yes	HS ^{5}	Other	Unemployed	No	No
ADP08	Female	61 to 70	Married	With partner	German	German	No	Abitur ^{1}	Admin.	Seeking work	Yes	Yes
ADP09	Female	51 to 60	Single	With rel.	German	German	Yes	FH-Reife ^{2}	Social area	Part-time	Yes	No
ADP10	Female	71 or older	Divorced	With rel.tives	German	German	Yes	HS ^{5}	Health area	In pension	No	No
PSYP01	Male	18 to 30	Unmarried	Alone	Bi-cultural	G. & others	No	Abitur ^{1}	IT	In training	Yes	Yes
PSYP02	Female	31 to 40	Married	Partner & rel.	German	German	No	Abitur ^{1}	Social area	Fulltime	No	No
PSYP03	Female	18 to 30	Unmarried	With rel.	German	German	No	Abitur ^{1}	Social area	In training	Yes	No
PSYP04	Female	18 to 30	Unmarried	Shared app.	German	German	No	Abitur ^{1}	Social area	Fulltime	No	No
PSYP05	Male	18 to 30	Unmarried	With partner	German	German	No	Abitur ^{1}	Social area	Fulltime	Yes	Yes
PSYP06	Female	18 to 30	Unmarried	Shared app.	German	German	Yes	MR ^{3}	Other	Disabled	Yes	Yes
PSYP07	Male	18 to 30	Unmarried Unmarried	With rel.	German	German	Yes	Abitur ^{1}	Other	Fulltime	Yes	No
PSYP08	Male	18 to 30	Unmarried	Shared app.	German	German	No	Abitur ^{1}	Social area	In training	No	Yes
PSYP09	Male	18 to 30	Unmarried	Shared app.	Bi-cultural	G. & others	Yes	Abitur ^{1}	Art & culture	Fulltime	Yes	Yes
PSYP10	Male	18 to 30		Alone	Bi-cultural	German	No	MR ^{3}	Social area	Fulltime	No	No
CHDP01	Male	51 to 60	Unmarried	Alone	German	German	n.a.	Abitur ^{1}	Trade	Unemployed	Yes	Yes
CHDP02	Female	61 to 70	n.a.	With partner	German	German	Yes	FH-Reife ^{2}	Economics	Part-time	Yes	Yes
CHDP03	Male	41 to 50	Unmarried	With partner	German	German	Yes	Abitur ^{1}	Other	Part-time	No	No

FBOC—Familial breast and ovarian cancer. PSY—Psychosis. AD—Alzheimer's disease. CHD—Coronary heart disease. [1] Abitur = Highest degree of German school system, general or subject-specific higher education entrance qualification. [2] Fachhochschulreife = Degree of German school system qualifying for general or subject-specific upper secondary school entrance. [3] Mittlere Reife = Middle degree of German school system qualifying for vocational school or comparable. [4] Polytechnische Oberschule = School form of former German Democratic Republic, comparable to degree of "Mittlere Reife" [5] Haupt-/Volksschulabschluss = Qualification of a general school form of middle education.

Appendix D

Table A5. Data material used for analysis.

	Audio Material	Transcripts	Questionnaires	Body Maps
FBOC	10:00 h	351 pages	10	10
AD	09:20 h	325 pages	10	8
CHD	04:10 h	60 pages	3	3
PSY	10:20 h	300 pages	10	10
Total	**~34:00 h**	**1036 pages**	**33**	**31**

References

1. Kickbusch, I. Health Governance: The Health Society. In *Health and Modernity*; Springer: New York, NY, USA, 2007; pp. 144–161. [CrossRef]
2. Sørensen, K.; van den Broucke, S.; Fullam, J.; Doyle, G.; Pelikan, J.; Slonska, Z.; Brand, H. Health Literacy and Public Health: A Systematic Review and Integration of Definitions and Models. *BMC Public Health* **2012**, 80. [CrossRef]
3. Kickbusch, I.; Pelikan, J.M.; Apfel, F.; Tsouros, A.D. Health Literacy. The solid facts. WHO Regional Office for Europe 2013. Available online: https://apps.who.int/iris/bitstream/handle/10665/128703/e96854.pdf (accessed on 10 September 2019).
4. Oliveira, G.S.d.; Errea, M.; Bialek, J.; Kendall, M.C.; McCarthy, R.J. The impact of health literacy on shared decision making before elective surgery. A propensity matched case control analysis. *BMC Health Serv. Res.* **2018**, *18*, 958. [CrossRef] [PubMed]
5. Muhanga, M.I.; Malungo, J.R.S. The what, why and how of health literacy: A systematic review of literature. *Int. J. Health* **2017**, *5*, 107–114. [CrossRef]
6. Abel, T.; Sommerhalder, K. Gesundheitskompetenz/Health Literacy. Das Konzept und seine Operationalisierung. *Bundesgesundheitsblatt Gesundh. Gesundh.* **2015**, *58*, 923–929. [CrossRef] [PubMed]
7. Samerski, S. Health literacy as a social practice. Social and empirical dimensions of knowledge on health and healthcare. *Soc. Sci. Med.* **2019**, *226*, 1–8. [CrossRef]
8. Smith, S.K.; Dixon, A.; Trevena, L.; Nutbeam, D.; McCaffery, K.J. Exploring patient involvement in healthcare decision making across different education and functional health literacy groups. *Soc. Sci. Med.* **2009**, *69*, 1805–1812. [CrossRef]
9. Altin, S.V.; Stock, S. The impact of health literacy, patient-centered communication and shared decision-making on patients' satisfaction with care received in German primary care practices. *BMC Health Serv. Res.* **2016**, *16*, 450. [CrossRef]
10. Joseph-Williams, N.; Williams, D.; Wood, F.; Lloyd, A.; Brain, K.; Thomas, N.; Prichard, A.; Goodland, A.; McGarrigle, H.; Sweetland, H.; et al. A descriptive model of shared decision making derived from routine implementation in clinical practice ('Implement-SDM'): Qualitative study. *Patient Educ. Couns.* **2019**, *102*, 1774–1785. [CrossRef]
11. Shen, H.-N.; Lin, C.-C.; Hoffmann, T.; Tsai, C.-Y.; Hou, W.-H.; Kuo, K.N. The relationship between health literacy and perceived shared decision making in patients with breast cancer. *Patient Educ. Couns.* **2019**, *102*, 360–366. [CrossRef]
12. Hauser, K.; Koerfer, A.; Kuhr, K.; Albus, C.; Herzig, S.; Matthes, J. Outcome-Relevant Effects of Shared Decision Making. *Dtsch. Ärzteblatt Int.* **2015**, *112*, 665–671. [CrossRef]
13. Stiggelbout, A.M.; Pieterse, A.H.; de Haes, J.C.J.M. Shared decision making. Concepts, evidence, and practice. *Patient Educ. Couns.* **2015**, *98*, 1172–1179. [CrossRef] [PubMed]
14. Koch, K. Informationen über Krebsfrüherkennung. Was wollen die Patienten? *Med. Klin.* **2003**, *98*, 400–403. [CrossRef] [PubMed]
15. Ishikawa, H.; Kiuchi, T. Health literacy and health communication. *Biopsychosoc. Med.* **2010**, *4*, 18. [CrossRef] [PubMed]

16. Schaefer, C.; Bitzer, E.M.; Dierks, M.L. für den Vorstandes DNGK. Mehr Organisationale Gesundheitskompetenz in die Gesundheitsversorgung bringen! Ein Positionspapier des DNGK. Köln, 15.11.2019. Available online: https://dngk.de/gesundheitskompetenz/or-ganisationale-gesundheitskompetenz-positionspapier-2019/ (accessed on 13 December 2019).
17. Chinn, D. Critical health literacy: A review and critical analysis. *Soc. Sci. Med.* **2011**, *73*, 60–67. [CrossRef]
18. Nutbeam, D. Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promot. Int.* **2000**, *15*, 259–267. [CrossRef]
19. Sørensen, K.; Pelikan, J.M.; Röthlin, F.; Ganahl, K.; Slonska, Z.; Doyle, G.; Fullam, J.; Kondilis, B.; Agrafiotis, D.; Uiters, E.; et al. Health literacy in Europe: Comparative results of the European health literacy survey (HLS-EU). *Eur. J. Public Health* **2015**, *25*, 1053–1058. [CrossRef]
20. Alper, J. *A Proposed Framework for Integration of Quality Performance Measures for Health Literacy, Cultural Competence, and Language Access Services: Proceedings of a Workshop. Roundtable on Health Literacy; Board on Population Health and Public Health Practice; Health and Medicine Division*; National Academies of Sciences, Engineering, and Medicine: Washington, DC, USA, 2018.
21. Haidl, T.K.; Seves, M.; Eggers, S.; Rostamzadeh, A.; Genske, A.; Jünger, S.; Woopen, C.; Jessen, F.; Ruhrmann, S.; Vogeley, K. Health literacy in clinical high-risk individuals for psychosis: A systematic mixed-methods review. *Early Interv. Psychiatry* **2019**, *13*, 1293–1309. [CrossRef]
22. Rostamzadeh, A.; Stapels, J.; Genske, A.; Haidl, T.; Jünger, S.; Seves, M.; Woopen, C.; Jessen, F. Health Literacy in Individuals at Risk for Alzheimer's Dementia: A Systematic Review. *J. Prev. Alzheimer's Dis.* **2019**, *6*, 1–9. [CrossRef]
23. Hellstern, M.; Peltzer, S.; Genske, A.; Jünger, S.; Woopen, C.; Albus, C. Health literacy in persons at risk of and patients with coronary heart disease: A systematic review. *Soc. Sci. Med.* **2020**, *245*, 112711.
24. Patton, M. *Qualitative Evaluation and Research Methods*; Beverly Hills: Sage, CA, USA, 1990.
25. Guest, G.; Bunce, A.; Johnson, L. How Many Interviews Are Enough? *Field Methods* **2016**, *18*, 59–82. [CrossRef]
26. Schütze, F. Biographieforschung und narratives Interview. *Neue Prax.* **1983**, *13*, 283–293.
27. Nohl, A.-M. *Interview und Dokumentarische Methode. Anleitungen für die Forschungspraxis*, 5th ed.; Springer VS: Wiesbaden, Germany, 2017. [CrossRef]
28. Lorke, M.; Schwegler, C.; Jünger, S. Re-claiming the power of definition—The value of reflexivity in research on mental health at risk. In *Qualitative Research Methods in Mental Health: Innovative and Collaborative Approaches Borcsa*; Willig, M.C., Ed.; Springer Nature: Cham, Germany, In press.
29. *VERBI Software. MAXQDA 2018*; VERBI Software: Berlin, Germany, 2019.
30. Gastaldo, D.; Rivas-Quarneti, N.; Magalhaes, L. Body-Map Storytelling as a Health Research Methodology. Blurred Lines Creating Clear Pictures. *FQS* **2018**, *19*, 1–26.
31. Merleau-Ponty, M. *Phänomenologie der Wahrnehmung*, 6th ed.; de Gruyter: Berlin, Germany, 1966.
32. Stamer, M.; Güthlin, C.; Holmberg, C.; Karbach, U.; Patzelt, C.; Meyer, T. Qualitative Studien in der Versorgungsforschung - Diskussionspapier, Teil 3. Qualität qualitativer Studien. *Gesundheitswesen* **2015**, *77*, 966–975. [CrossRef] [PubMed]
33. Lincoln, Y.S.; Guba, E. *Naturalistic Inquiry*; Sage: London, UK, 1985.
34. Breuer, F.; Muckel, P.; Dieris, B. *Reflexive Grounded Theory. Eine Einführung für die Forschungspraxis*, 4th ed.; Springer VS: Wiesbaden, Germany, 2019.
35. Saunders, B.; Sim, J.; Kingstone, T.; Baker, S.; Waterfield, J.; Bartlam, B.; Burroughs, H.; Jinks, C. Saturation in qualitative research: Exploring its conceptualization and operationalization. *Q. Quant* **2018**, *52*, 1893–1907. [CrossRef] [PubMed]
36. Strübing, J.; Hirschauer, S.; Ayaß, R.; Krähnke, U.; Scheffer, T. Gütekriterien qualitativer Sozialforschung. *Ein Diskuss. Z. Für Soziologie* **2018**, *47*, 83–100.
37. Denzin, N. *The Research Act in Sociology*; Butterworth: London, UK, 1970.
38. Park, C.L.; Folkman, S. Meaning in the Context of Stress and Coping. *Rev. Gen. Psychol.* **1997**, *1*, 115–144. [CrossRef]
39. Slovic, P.; Finuncane, M.L.; Peters, E.; MacGregor, D.G. Risk as Analysis and Risk as Feelings: Some Thoughts about Affect, Reason, Risk and Rationality. *Risk Anal.* **2004**, *24*, 311–322. [CrossRef]
40. Nutbeam, D. The evolving concept of health literacy. *Soc. Sci. Med.* **2008**, *67*, 2072–2078. [CrossRef]
41. Kleinman, A. *The Illness Narratives: Suffering, Healing, and the Human Condition*; Basic Books: New York, NY, USA, 1988; p. 304.

42. Greenhalgh, T.; Robb, N.; Scambler, G. Communicative and strategic action in interpreted consultations in primary health care: A Habermasian perspective. *Soc. Sci. Med.* **2006**, *63*, 1170–1187. [CrossRef]
43. Papen, U. Informal, incidental and ad hoc: The information-seeking and learning strategies of health care patients. *Lang. Educ.* **2012**, *26*, 105–119. [CrossRef]
44. Fairbrother, H.; Curtis, P.; Doyder, E. Making health information meaningful: Children's health literacy practices. *Ssm Popul. Health* **2016**, *2*, 476–484. [CrossRef] [PubMed]
45. Habermas, J. *Theorie des Kommunikativen Handelns*; Suhrkamp: Frankfurt, Germany, 1981.
46. Carel, H.; Kidd, I.J. Epistemic injustice in healthcare: A philosophical analysis. *Med. Health Care Philos.* **2014**, *17*, 529–540. [CrossRef] [PubMed]
47. DasGupta, S.; Charon, R. Personal Illness Narratives: Using Refelctive Writing to Teach Empathy. *Acad. Med.* **2004**, *79*, 351–356. [CrossRef] [PubMed]
48. Dierks, M.-L. Brustkrebs-Früherkennung: Einstellungen und Motive von Frauen zur Mammographie. In *Die Kontroverse um die Brustkrebs-Früherkennung*; Koppelin, F., Müller, R., Keil, A., Hauffe, U., Eds.; Huber: Bern, Switzerland, 2001; pp. 109–116.
49. Piepolii, M.F.; Hoes, A.W.; Agewall, S.; Albus, C.; Brotons, C.; Catapano, A.L.; Cooney, M.-T.; Corrà, U.; Cosyns, B.; Deaton, C.; et al. 2016 European Guidelines on cardiovascular disease prevention in clinical practice: The Sixth Joint Task Force of the European Society of Cardiology and Other Societies on Cardiovascular Disease Prevention in Clinical Practice (constituted by representatives of 10 societies and by invited experts). *Eur. Heart J.* **2016**, *37*, 2315–2381. [CrossRef]

2.3.2 CULTURE IN MENTAL HEALTH: DEFINING RISK AND THE VALUE OF REFLEXIVITY

Article 2: Lorke, Mariya*; Schwegler, Carolin*; Jünger, Saskia (2021): Re-claiming the Power of Definition - The Value of Reflexivity in Research on Mental Health at Risk. In: Maria Borcsa und Carla Willig (Eds.): *Qualitative Research Methods in Mental Health. Innovative and collaborative approache*s. Cham: Springer, pp. 135–165.

The second contribution deepens the notion of adequate understanding between doctors and advice seekers, while focusing on the field of mental health. On one hand, being confronted with the idea of a health risk itself challenges a person's well-being. On the other hand, the definition of risk in mental health lies with professionals requiring persons to find a balance between threat and confidence. The negotiation of the *power of definition* with respect to health risk takes place on three different levels – advice seekers, doctors, and researchers – and builds the scaffold of this article.

This article is based on two different projects realised in the period between 2016 and 2019. It originated from a collaborative conference panel on risk in mental health and focuses both on the process of meaning making and on the research process itself. In the context of the research question of this thesis, the article deepens our understanding of risk with a focus on mental health. Meanwhile it suggests how research on health literacy may be carried out in a culture-sensitive way through extensive researcher reflexion. Twenty narrative interviews with persons facing a mental health risk of developing psychosis or Alzheimer's disease were analysed in a circular process, using complementing methodological perspectives from two disciplines: ethnology and linguistics.

The findings of this article are grounded in the idea that persons faced with a health risk construct their personal narratives to find a meaningful way to manage their situation embedded in their biographical and social context. It also invites a reflection on the potential of qualitative research in re-claiming the power of definition, offering the opportunity for a co-construction of concepts such as risk, vulnerability and mental health.

In the context of the overarching research question of this thesis, this article provides insight not only into the perceptions of risk among individuals, but also into ethical and methodological issues of assessing concepts such as *risk* or *vulnerability* in the context of health and health literacy. It emphasises the importance of (self-) reflexivity in conducting research in this field. For future research, such methodological reflection on these issues may be beneficial when dealing with the tension between a standardised biomedical conception, and an open, bottom-up approach to health knowledge in a medically oriented scientific environment.

Chapter 7

Re-claiming the Power of Definition—The Value of Reflexivity in Research on Mental Health at Risk

Mariya Lorke, Carolin Schwegler, and Saskia Jünger

Abstract Being confronted with health risks implies challenges to mental health and well-being, requiring persons to find a balance between threat and confidence. The 'power of definition' with respect to health risks predominantly lies with professionals, implying that there is one appropriate way of understanding and interpreting risk-related information. This chapter will invite for a reflection on the potential of qualitative research in re-claiming the power of definition, offering the opportunity for a co-construction of concepts such as risk, vulnerability, and mental health. The aim is to highlight the particular value of different methodological approaches for opening up definitional spaces between scientists and research participants. It is grounded in the assumption that persons faced with a health risk construct their personal narratives to find a meaningful way to manage their situation, embedded in their biographical and social context. Narrative interviews with persons faced with a mental health risk were analysed in a circular process using complementing methodological perspectives from two disciplines: ethnology and linguistics. The findings were situated within a sociology of knowledge framework, focusing on the power of definition concerning a person's health and health risks. Herein, particular attention was drawn to ethical and methodological issues of assessing concepts such as 'risk' or 'vulnerability'; and the importance of (self-)reflexivity in conducting research in this field. Methodological reflection on these issues may contribute to constructively dealing with the tension between a standardised biomedical conception and an open, bottom-up approach to health knowledge in a medically oriented scientific environment.

Keywords Mental health risk · Risk perception · Dementia · Psychosis · Narrative approach · Semantics · Linguistic analysis · Ethnological approach · Sociology of knowledge · Meaning-making

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M. Lorke · C. Schwegler
Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health, University of Cologne, Cologne, Germany

S. Jünger (✉)
Department of Community Health, University of Applied Health Sciences, Bochum, Germany
e-mail: saskia.juenger@hs-gesundheit.de

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Introduction: Mental Health 'at Risk'—Challenging Definitions and Methodologies

From a sociology of knowledge perspective, knowledge is thought to be created through a process of discursive construction (Berger & Luckmann, 1966). Scientific knowledge—including medical 'facts'—is conceived of as socially, culturally, and historically contingent (Fleck, 1979). Of central interest is the process of the social production, transformation, and circulation of knowledge (Keller, 2011). This includes the roles, the positions, and the level of (non-)authority assigned to different stakeholders within the whole research undertaking.

While there are promising approaches such as user involvement or participatory, user-led research (e.g. Byrne & Morrison, 2010), the field of mental health research is still shaped by the predominant Western[1] paradigm of biomedical research. This has implications for the entire research process, including the definition of research questions (who defines them and which questions are considered relevant), theoretical foundations, the choice of methodologies and methods of data collection and analysis, the interpretation of findings and the conclusions drawn from these, as well as the publication and implementation of outcomes. As a consequence, the way of doing research shapes the reality of 'mental health'.

This chapter will invite a reflection on the potential of qualitative research in re-claiming the power of definition concerning mental health. Focusing on the experiences of persons 'at risk' for a mental health problem, it aims at offering the opportunity for a co-construction of concepts such as risk, vulnerability, and mental and (neuro)cognitive health. The aim is to highlight the particular value of the merger of different methodological approaches for opening up definitional spaces between scientists and research participants. It is grounded in the assumption that persons faced with a health risk construct their personal narratives in order to find a meaningful way to manage their situation and to (re-)gain a sense of agency, embedded in their biographical and social context. Drawing on the technique of (self-)reflexivity,[2] the potential and the challenges of qualitative research with regard to mental health risk will be discussed.

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[1] The term 'Western'—despite not being undisputed—is used in this chapter in order to describe a "*mind-set, a worldview that is a product of the development of European culture and diffused into other nations like North-America*" (Ermine, Sinclair, & Jeffery, 2004, p. 5). 'Western' comprises an archive of knowledge and systems, rules and values, as well as intellectual, political, economic, cultural, and social constructs extracted from and characteristic of Europe and the Western hemisphere (Pellegrino, 1992; Smith, 2012). It includes fundamental attitudes to nature, reality, and knowledge (Sachs-Jeantet, Sagasti, & Salomon, 1994), hereby shaping the institutionalised social system within which knowledge production is embedded.

[2] We use the term (self-)reflexivity in the sense of a self-critique concerning the process of conducting research and producing knowledge. This self-critique demands examining our role as researchers, reflecting on how our particular background (such as our disciplinary and institutional socialisation, biography, values and attitudes, bodily constitution, or relationship to the interviewees) may interact with the research process, and on the power of presentation when publishing this research (Breuer, Muckel, & Dieris, 2019).

Being 'at Risk' in the Context of Dementia and Psychosis

Techno-scientific progress in biomedicine implies increasing opportunities for the early detection of disease risks (Aronowitz, 2009; Clarke, Shim, Mamo, Fosket, & Fishman, 2003). Advances in the field of predictive and preventive medicine can be considered a blessing, since ever earlier prediction is associated with the promise of better chances to prevent and treat disease and suffering. However, being confronted with health risks also implies challenges to mental health and well-being, requiring persons to find a balance between threat and confidence (Gillespie, 2012).

Both for psychosis and for dementia due to Alzheimer's disease (AD), efforts during the past decades were—and still are—directed at as precise and as early as possible diagnosis of prodromal stages of the conditions long before the full clinical picture can be observed.

In the case of AD, research aims to clinically identify early symptomatic stages such as mild cognitive impairment (MCI) or the even preceding subjective cognitive decline (SCD) (Albert et al., 2011; Jessen et al., 2014). MCI is associated with a risk for the development of dementia which is increasing in combination with a biomarker-positive testing (cerebral amyloid deposition and aggregation of tau protein; Jack et al., 2018).[3] In the case of psychosis, symptom assessment checklists and criteria for a 'high-risk' state were developed to identify the impending risk for transition to psychosis. Terms such as the clinical-high-risk state for psychosis (CHR), at-risk mental state (ARMS), or ultra-high-risk state (UHR) are used to describe the condition of individuals assumed to be in a pre-psychotic phase and to identify the impending risk for transition to psychosis (Fusar-Poli, 2017).

While there is agreement that early intervention is beneficial in terms of a person's long-term development, there is currently no unequivocal evidence concerning the most effective and efficient preventive interventions for either conditions. Concerning treatment options, in case of AD no cure exists to date. Meanwhile, the combination and probabilistic form of medical risk factors leaves the individual unclear concerning their relative effect, and without certainty about the future. Notwithstanding this, the 'power of definition' with respect to health risks predominantly lies with professionals, i.e., scientists or health professionals, implying that there is one appropriate way of understanding and interpreting risk-related information, and transforming it into health-promoting behaviour.

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[3] MCI is connected with a 33% risk for developing dementia (Mitchell & Shiri-Feshki, 2009). MCI in combination with biomarker-based AD is associated with an increased risk of up to 59% for the development of dementia in the next three years (Vos et al., 2015). If the biomarkers remain inconspicuous or partially inconspicuous, risk probabilities of 5 and 23% apply. This means, so-called persons at risk do not only have to deal with the designation 'persons at risk' or 'MCI-patients' but also with the medically determined probabilistic understanding of risk (cf. Jack et al., 2018).

Making Sense of Risk—Risk Literacy and Meaning-Making in Mental Health

People confronted with a health risk need to make sense of the information communicated to them, such as probabilities, percentages, prognoses, as well as recommendations regarding prevention and treatment. Meaning-making can be considered as crucial in the process of coping with a challenging situation in life (Park & Folkman, 1997). Risk literacy is defined in terms of mathematical and logical transfer skills such as understanding percentages, estimating an individual risk based on a population risk, and deriving appropriate decisions and actions from the 'correct' risk appraisal (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2007). However, critical health literacy as the capacity to critically appraise information against the background of one's personal lifeworld, values, and preferences, is much less in the focus of research and public debates (Sykes, Wills, Rowlands, & Popple, 2013). Hence, it can be argued that the capacity to make sense of one's own health risk and to translate this meaning into some form of coping is predominantly defined from a scientists' and health professionals' perspective, and is associated with patients' virtues of listening to and adhering to medical advice. In relation to risk literacy, Samerski (2013) describes the phenomenon of 'epistemic confusion' since a person needs to conflate a statistical risk profile with his or her personal situation in order to be considered as 'risk literate'.

Scientific Knowledge Production and Power Relations in Mental Health

Definitions of at-risk states in mental health require discussions about the transition between 'order' and 'disorder'. Psychiatric and neurocognitive diagnoses are used to categorise the emotional and behavioural traits to be considered as 'disordered', hereby setting standards for 'normality' (Albert et al., 2011; Timimi, 2014).[4] The conception of 'disorder' is highly debated in the field of mental health (Frances, 2014; Gronemeyer, 2013; Schaarschmidt, 2018; Wakefield, 2012). Psychiatry claims for itself the power of definition as to which behaviour or cognitive state is healthy and which is deviant, pathological, and in need of treatment. Discussions about the nature of a mental disorder, its aetiology, and the validity of risk factors are led among clinicians and scientists, while people experiencing the risk-related symptoms or syndromes are usually understood as the recipients of the resulting knowledge,

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[4] All preliminary stages of dementia symptoms are defined as still being able to perform everyday tasks without larger limitation, even if now and then it may be necessary to overcome word finding disorders, forgetfulness and disorientation (as with MCI). Only in a second step biomedical markers of risk become relevant, but then with a strong classification and the label 'risk for AD', not only cognitive decline (of any category).

not as experts entitled to partake in the debate or in the planning of their therapeutic process. Moreover, explanatory models tend to be increasingly dominated by biomedical perspectives (Bearden & Forsyth, 2018), while other approaches such as psycho-dynamic explanations or patients' self-experience are upstaged (Schultze-Lutter, Schmidt, & Theodoridou, 2018). At the same time, mental health problems and cognitive decline are seriously stigmatised, resulting in social labels based on arbitrary societal and medical norms. For example, medical, scientific and public discourses about dementia or schizophrenia tend to be catastrophising (e.g. Zeilig, 2014), shaping the political, social, and medical narratives around AD and psychosis. In this chapter, we aim at adopting a bottom-up approach to gain an in-depth understanding of the individual constructions of meaning among persons whose mental health is considered being at risk: How do they make sense of this information? How do they describe their situation, either with or without referring to the term risk? What are the implications of the awareness of their risk for their everyday life?

Researching Mental Health 'at Risk': Methodology and Method

Narrative interviews with persons faced with a health risk in different clinical fields (psychosis and dementia due to AD) from two studies (RisKomp, hereinafter 'study on psychosis' and PreDADQoL (cf. Rostamzadeh et al., in press), hereinafter 'study on AD') will constitute the empirical base for the analyses in this chapter. The differences between the approaches in both studies are described in more detail in Box 1. Overall, narratives will be analysed in a circular process using complementing methodological perspectives from two disciplines: ethnology[5] and linguistics. Herein, particular attention will be drawn to methodological and ethical issues of assessing concepts such as 'risk' and 'vulnerability'; as well as the importance of (self-)reflexivity in conducting research in this field.

The two studies we refer to in this chapter both employ a qualitative design emphasising significant similarities in terms of the value of narratives. We aim at addressing the benefits and challenges of mental health research based on narrative knowledge, outlining the role of (self-)reflexivity in the research process by merging the findings from 20 interviews (10 from each study). In the following paragraphs, we will provide a short overview of the methodology used in both studies, focusing on sampling strategy, interviews, reflection, and analysis.

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[5] For this contribution, we employed an *ethnological approach* to make use of a theoretical framework for comparative analysis with the aim to gain insight into both cultural phenomena and research processes concerning 'persons at risk' of psychosis or AD. While *ethnography* refers to a methodological approach based on fieldwork for the in-depth study of a particular culture, *ethnology* allows for comparison and the identification of overarching structures, principles, and relationships (Flemming, 2010). *An ethnographer is constructing a theory that will make intelligible what goes on in a particular social universe. A comparativist (i.e., an ethnologist; author's note) is trying to find principles common to many different universes* (Goodenough, 1956, p. 37).

Sampling Strategy

Since there are hardly any evidence-based guidelines for the ideal size of the sample (Guest, Bunce, & Johnson, 2006), the decision on the sample size was taken based on the research question, the choice of methods, the sampling strategy and the availability of research resources. Also, we took the conventions in research literature and practice (Mason, 2010) into consideration. Our project partners[6] recruited the study participants according to collaboratively defined inclusion and exclusion research criteria, based on medical indications.

Data Collection

The qualitative data of 'persons at risk' were collected by means of narrative interviews (psychosis) and episodic interviews with a main narrative and a minor semantic part (AD) which both led to a significant proportion of uninterrupted narratives and free-flowing interactions (see methodological details below). As a central method of ethnographic as well as linguistic approaches (Deppermann, 2013; Groleau, Young, & Kirmayer, 2006), narrative and episodic interviews produce data that can give an insight into a person's individual perceptions, stratifications of experience, and entanglements of life-events (Schütze, 1983). A particular feature of our study on AD was the inclusion of one close other (e.g. spouse or close family member) with each patient. It is a common practice in memory clinics that a relative is closely involved in the diagnostic procedures and the counselling appointments. It was hence our aim to learn more about their individual perception of the (troubling) prospect to be a caregiver or even the present experience of being a 'pre-caregiver' (Largent & Karlawish, 2019). The dyads (of patients and close others) were interviewed separately but directly one after another.

Methodologically, we aimed at generating hypotheses on how persons confronted with the condition of being 'at risk' interpret this information and how they make sense of it in the context of their lifeworld. We therefore strived for a participatory perspective in defining our central concepts based on our interviewees' individual perceptions and experiences, in order to generate theories on the subjective meaning of risk grounded in these empirical findings, and to let them re-claim the power of definition.

With a view to such explorative outcomes, the methods of the guided narrative interview (Nohl, 2017) and the episodic interview (Flick, 1997) seemed to provide a fruitful ground for data collection (cf. Box 1). In both studies, a topic guide was used flexibly in the interview process in order to provide adequate space for the individual narrative construction. By asking further in-depth questions on aspects brought up

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[6] In the case of psychosis, the FETZ (Cologne Early Recognition and Intervention Centre for mental crisis), and in the case of AD, the ZfG (Cologne Memory Clinic), both at the department of Psychiatry and Psychotherapy at the University Clinic of Cologne, Germany.

by the interviewee or questions on concrete situations of experiences the interviewer could stimulate the generation of additional complementing and/or more detailed accounts. This can provide not only information on the personal background and perceptions of risk, but also on how these are described in the interviewees' everyday language and embedded in social processes and cultural contexts.

Interview Procedures

In the study on psychosis, we used narrative interviews with the aim to put our interviewees' own perspective, interpretation, and subjective constructions of meaning at the centre of their accounts. A flexible topic guide was employed to allow for the unfolding of free narratives and the emergence of unexpected topics. We started the interview with an open question on a concrete situation in which individuals got confronted for the first time with the information of an increased risk. To elaborate more in depth on issues raised during the interviewees' initial open narrative, focused questions were used for explication, reflexion, or to invite for more detailed accounts (Groleau et al., 2006; Nohl, 2017). For in-depth exploration, the interview guide included topics based on existing research (family, identity, othering, health literacy) and additional questions formulated by the research team during the preparation phase. These were mobilised flexibly throughout the interview procedure (opening/formal phase, opening question, additional in-depth questions, closing phase), taking up the interviewees' preceding accounts and referring to their wording.

In the study on AD, we used episodic interviews as a useful approach to relevant experiences in life. The underlying idea is the differentiation of so-called world knowledge into two parts: Firstly, episodic knowledge which comprises knowledge that is linked to concrete circumstances (time, space, persons, events, situations), secondly, semantic knowledge which is more abstract, generalised, and decontextualised from specific situations and events (Flick, 1997). In the episodic part, which leads to narrations, the interviewer asks (chronologically) for specific situations from the life of the interviewee (before and after risk prediction and within those two times for situations of the everyday life, social environment, current situation, expectations, visions for the future, hopes and worries) in order to gain episodic knowledge. It is particularly important for the later linguistic analysis that central terms are not predetermined and that the questions are as 'innocuous' as possible from a lexical point of view. For example, "Can you describe to me how and why you got here?" (the interviews took place in the memory clinic). In-depth question: "Can you tell me a specific situation that explains to me how you felt about it?". With a reduction to deictics (here, it) the interviewees are invited to select and moreover name the central aspects themselves.

The last part of the episodic interview focuses on semantic knowledge which is achieved through semantic questions, i.e. questions for personal definitions, perceptions and understandings of certain terms which were used by the interviewee during the interview or are generally of interest for the study. The statements can be combined and contrasted with the narratives and also help to interpret certain statements of the interviewees (as well as the quantitative data of the study; cf. Rostamzadeh et al. (in press)).

Reflexivity

In order to make researcher's thoughts, feelings and subjective factors in the research process visible, we decided to employ different reflection methods in the two studies.

In the case of psychosis, we developed a reflection-tool integrated in the interview guide consisting of two subparts—notes (descriptions) and memos (interpretations and feelings). It enabled the researchers not only to analyse the 'subjectivity factor' in the overall analysis process, but also to reflect their own attitude and behaviour after each interview and so contribute to an increased richness of data.

In the case of our study on AD, we added metadata to each interview as material for the reflexive process. It includes additional aspects of the interview that cannot or was not recorded via audio taping, conversations and expression from the counselling physician, and impressions from the first meeting with both participants from one dyad (patient plus one close other). Concerning the analysed interview data, the linguistic approach of the interactional analysis (Deppermann, 2008) is not only focusing on expressions the interviewee utters but also the interviewer's assertions. In this way, the interviewer's statements also become objects of the (team) analysis and evaluation which encourages the reflection process. Since linguistic analysis is focusing on 'how' and not only 'what' was communicated, it is necessary for the interviewer to try to avoid certain key terms and predeterminations of vocabulary.

Analysis

In both studies, we focused on the multi-perspectivity of perception and strived to reveal various levels and modalities of the concepts concerned. The following paragraphs will demonstrate this by means of a detailed description of findings concerning the interviewees' perception and appraisal of their condition of being 'at risk', and by reflections on the methodological opportunities and challenges we encountered throughout the research process. The data used in the following discussion part originate from the interviews (psychosis and AD), the reflection-tools (psychosis), and single aspects of the metadata protocols (AD) (Box 1).

In the field of health sciences, interviewees' statements are often analysed from a thematic point of view, considering the interview as textual access to the social or psychological reality of interviewees, hence representing a more realist approach to data analysis (Willig, 2012). By contrast, in our analysis we strived for a more relativist perspective, understanding the interview narratives as situated co-constructions between interviewee and researcher.

Our *ethnological approach* was embedded in the *Reflexive Grounded Theory* methodology (Breuer et al., 2019). To enrich and complete our core data set of narrative interviews, we worked with additional data in the form of field notes, memos, and "thick descriptions" (Geertz, 1973) based on our self-reflection tools. Furthermore, we integrated reflexivity in the process of data analysis as a tool to make the researchers' subjectivity visible (Reichertz, 2015). Apart from this methodological triangulation (Denzin, 1970), we also strived for a researcher and theory triangulation which can be considered as crucial for an ethnological approach to our research field. The involvement of different disciplines within the research team allowed for a complex range of perspectives on the data, approaching it from different angles in terms of concepts and theoretical frameworks. The ultimate goals of our analysis were (1) to get as close as possible to the actors and let them speak for themselves, in their images and narratives; and (2) to generate preliminary theoretical explanations based on the empirical data.

The *linguistic approach* of interactional analysis (Deppermann, 2008) understands interviews as situated practice in which social structures of meaning are jointly created. Both the interviewees' and the interviewers' assertions are focused upon equitably during the process of analysis (even though the research questions and overall results might focus the interviewees' perspective only). As Deppermann (2013) points out, this approach prevents the analysis of the interviewee's statements without the reflection and analysis of what the interviewer emits or adds to the conversation—and most importantly 'how' he or she communicates. For this reason, it is essential that the audio-data is transcribed into the linguistic GAT2 system (Selting et al., 2009) which is close to the "Jefferson transcription system" and implies that overlaps of conversation elements, interruptions, and pauses are accurately represented. Furthermore, it appears to be a fruitful approach to consider the questions 'what', 'how', and 'why' successively and iteratively during the analytical process to shed light on relevant spoken elements, linguistic practices, forms, and semantic aspects as well as functions of those (Birkner, 2006).

For an *integration of both the linguistic and ethnographic approach*, we employed a comparative meta-analysis of the existing data in both projects in order to explore in-depth the findings and the methodological lessons learned from doing research on risk in the context of mental health. After data from the two projects had been analysed separately to answer the respective research questions, we discussed our findings and observations across both projects within the research team; and we compared our category systems in terms of intersections and differences. In this way, we identified our central categories with regard to the condition of being at risk (cf. section 'Insights from the Interviews: Naming, Explaining, and Coping'): naming, explaining, and coping; and we discovered overarching issues in terms of reflecting on our methodology and the research process (cf. section 'Methodological Reflection: Negotiating Vulnerability and Normality' and Box 2).

Box 1: Overview of the two studies presented in this chapter

	Study on AD	Study on psychosis
Name	Ethical and Legal Framework for Predictive Diagnosis of Alzheimer's Disease: Quality of Life of Individuals at Risk and their Close Others (PreDADQoL)	Health Literacy in Persons at Risk—From Information to Action (RisKomp)
Project leaders	Ceres, the Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health, University of Cologne University Hospital Cologne Fundació ACE Barcelona	Ceres, the Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health, University of Cologne University Hospital Cologne
Study design	Binational longitudinal mixed methods study including an ethical and legal framework (cf. Rostamzadeh et al., in press)	Multi-method study including systematic reviews and qualitative interviews
Aims of the study	(1) to determine attitudes and expectations towards the AD-risk prediction and elucidate the effect on the participants' QoL in order to provide a guideline for information and counselling; (2) to discover semantic content and multiperspectivity of concepts such as risk, QoL, satisfaction and well-being	(1) to better understand health literacy of 'persons at risk' in four different clinical fields, (2) to underpin it conceptually and (3) to make it fruitful for health care
Participants	Persons at risk for dementia due to AD, namely patients with MCI, who can optionally undergo a risk prediction, and one close other (family member; as an individual, not as a proxy informant) each (person at risk + close other = dyads)	Persons with an increased risk of developing a certain disease or an unfavourable course of the disease in four clinical fields: familial breast and ovarian cancer, coronary heart disease, psychosis and AD
Data of the project	Quantitative data from 50 dyads at 3 visits (in Cologne and Barcelona), qualitative data from 15 dyads at 2 visits from the German side only	Qualitative data from 40 narrative interviews (10 in each clinical field), 40 body-maps and 40 field notes data sets
Data used for this chapter	10 episodic interviews with narrative parts of around 30 min each, 5 from baseline (before predictive testing), 5 from the 3-month follow-up	10 narrative interviews with an average duration of 61 min, 10 field notes data sets
Data type	Audio-data, transcripts (GAT 2, basic)	Audio-data, transcripts, field notes data sets
Collection of metadata	Demographic data, medical records/explanations, interview metadata (interviewers' impressions and crucial non-verbal aspects on the background, the atmosphere or information the physicians shared with us in advance/after the interview) → used only additionally	Socio-demographic data (age, sex, marital status, cultural, educational and professional/occupational background) and field notes

(continued)

(continued)

	Study on AD	Study on psychosis
Method	Episodic interviews with a main narrative and a minor semantic part (Flick, 1997)	Narrative interviews (Nohl, 2017)
Interview topics	Everyday life, social environment, current situation, expectations, visions for the future, hopes and worries	Perceptions and experiences of risk, health and sickness, identity, family, everyday life, current situation, coping strategies, otherness and health literacy
Procedure	Chronological according to the participants' experiences, beginning with the first impression or feeling of impairment (at baseline), impressions and feelings since the risk disclosure (at 3-month follow-up), both thematically open	(1) Open question ("Tell me about the first time when you were confronted with the topic of being at risk of developing psychosis?"), (2) free part and (3) body-mapping exercise ("How would you depict the feeling of being at risk of developing a psychosis?") with comment on the drawing
Significant aspect	Questions and in-depth questions on concrete situations and experiences, semantic questions	Narrative interviews combined with memos (to make the researcher subjectivity visible)
Method of analysis	Linguistic interaction analysis with a focus on lexical and semantical aspects; metadata protocols as an analytical support, but focused on the aspects of perception that are revealed trough individual linguistic expressions (Birkner, 2006; Deppermann, 2008, 2013)	The process of data analysis was embedded in the Reflexive Grounded Theory (Breuer et al., 2019) based on three pools of data—the interviews (as audio and transcription), the body maps (incl. the verbal comments on them) and the field notes data sets (in the form of self-reflexion tools)

Results and Discussion

The following section consists of two subparts, which draw a common line of methodological reflection across both projects, hereby emphasising the opportunities and challenges that our teams faced doing qualitative research on mental health within the context of risk and medical prediction. It encompasses *content-led* results in negotiating vulnerability and normality from a bottom-up perspective ('Insights from the Interviews: Naming, Explaining, and Coping'), and *process-led* reflexivity discussing the interview as a method of data generation, the negotiation of roles and responsibilities, as well as ethical reflections throughout the research processes ('Methodological Reflection: Negotiating Vulnerability and Normality'). The sub-sections mirror methodological opportunities and challenges in the field of tension between biomedical understandings of risk and a person-oriented bottom-up approach.

Insights from the Interviews: Naming, Explaining, and Coping

The notions of vulnerability and normality play a central role in all steps of the research process and in all levels of content generation. Defining the persons at risk as a vulnerable group in the beginning of the research process challenged the idea of mental resilience, the explanatory models of risk, and raised questions about the factors that trigger and/or regulate this vulnerable condition. We will present findings from both studies along three categories that we identified in the interviews with regard to the condition of 'being at risk': naming, explaining and coping. These categories are selected because they thematically summarise essential stages of the process that occurs within the scope of 'being at risk' or 'learning to be at risk'.

Naming

The naming of risk can have diverse implications in the context of different conditions, as the following comparison of our interviews will illustrate. During the interviews with persons at risk of psychosis, it became clear that the naming of this condition in the context of the diagnostic process had been perceived as a relief rather than a threat. One reason was the affirmation of one's own perceptions, and an 'acquittal' of being suspected of working oneself up into the perception of strange sensations, and all symptoms being just an imagination:

PSYP03 (Interviewee; study on psychosis)[7]

When you talk to some friends or so about it, who don't really know anything about it […] I've already heard it once or twice: Yes, I think you're exaggerating a bit, or something. That is of course […] hurtful. But if someone who's studied that and says that, uh, so… says: Yes […] You're right, you have that… and you actually have a problem, that's very affirmative… in, so, for me […]. Well, it didn't scare me now either, but I thought by myself: Now I know […], I can do something about it. That's the first step.

The hard-to-communicate experience of ambiguous symptoms was replaced by a tangible and nameable condition of being at risk of developing psychosis. The latter might be perceived as more favourable, presumably because it can be explained by biomedical knowledge and is more strongly connected to body processes.

The impact of risk on people's lives and the notion of naming and vulnerability also became obvious in terms of the role as a "patient", which reveals the close relation between the phase of naming and explaining the 'at risk' condition. This role could be seen pragmatically, willingly engaging oneself with it, as reflected in the first quotation; or as an enigma, to a certain extent associated with a loss of definitional control, as emerging from the second quotation:

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[7] The interviews were conducted in German language. Quotations were literally translated by the research team; for better readability, language and grammar were smoothened (e.g. omission of repetitions).

PSYP01 (Study on psychosis; P: interviewee; I: interviewer)

P: (laughs) Has now rented a, uh, practice or so, a room and I am now one of the first patients, so.

I: Oh so, ok. Because

P: =Is it called 'patients'?

I: Yes, there are always discussions about it. Some say clients, others say patients=

P: =Bähh, clients. Like somehow it's a … as if I give her money (laughs)=

I: =Yes, I, uh, I always find that difficult, because I actually also don't want to say 'patient' either, because you are now my interview partner, for example. But when you're so medically minded, you automatically say 'patient'.

P: =Yes, so I don't find anything reprehensible about the term, so, it, I'm just de facto one.

PSYP04 (Interviewee; study on psychosis)

And yet the feeling afterwards was as follows: Now somehow for one and a half or two hours we have spoken to each other and described the problem as it were and that from this comes a diagnosis, yes, a diagnosis, or that somebody somehow can get an idea of something, uh, … and just then with such standardised questionnaires somehow, uh, therefore, hard to imagine… for me, or… yes, if you are perhaps not a specialist, uh, that you then have a clear picture of what is happening with these diagnostic instruments.

In our interviews with persons at risk for AD, the 'possibility to give a name' to the situation after the predictive biomarker testing sometimes is not experienced as a relief but as a reason for their behaviour and a confirmation of their perceived cognitive problems or the distrust towards their own mind. One participant (AD04, MCI patient) pointed out that with a conspicuous test result she "had something to say" when someone wonders why she "behaves so strangely". Her husband (AD04, close other), who was interviewed as part of her dyad, supported the positive effect in his narrations. He mentioned that with a conspicuous test result he knew that his wife "did not deliberately ignore him" but "acted in her disease". In this case, a medical label in the form of a risk status helps especially (close) others to classify the perceived 'abnormal behaviour' and to find explanations for it—even if those aren't entirely certain.

In the baseline interview—before the predictive testing—most of the participants showed a strong reaction to the terms 'dementia' or 'Alzheimer's disease dementia', even if the interviewer did not use the word in her own expression, but only referred to the associated documents or situations in the interviewee's life. This reveals a different attitude to 'naming' at baseline compared to the follow-up interview after the predictive testing. In the baseline-interviews from our study on AD, some participants started to tell a story about a specific situation in which the idea of 'being at risk for dementia' simply became 'dementia' and led to a different treatment or even discriminating actions as in the interview segment below (AD01). For the linguistic analysis, it is crucial that the naming is performed by the participants themselves to be able to analyse 'how' and 'why' something is communicated.

AD01 (Study on AD, baseline interview segment with an MCI patient)

```
204 P:  on the referral he wrote dementia (.) he knows ehm he doesn't KNOW what that
205     I have dementia -
206 I:  the family doctor?
207     no that is true (-) he doesn't [know;]
208 P:                                 [ yes ]
209 I:  assumed maybe [non that ] was his assOMPtion.
210 P:                [yes yes- ]
211     he assumed that I have dementia;
212 I:  hmhm.
213 P:  that's why the reception the receptionists are eh were suddenly different (.)
214     different to me;
215 I:  oh okay I understand
216     but this is they don't mean it (.) do you think they mean is in a harmful way?
217 P:  no no ((laughs))they a shout over as if I were deaf or so and MRS SCHMI::::D
218     ((anonymized)) as if I was not normal -
219     they are they don't know how to talk those to those with dementia ((laughs)),
220 I:  you are more experienced there right you gathered experience with your mother how
221     to handle this did you say before;
222 P:  yesyes -
223 I:  and the receptionists maybe learn when there is written dementia on the sheet of
        paper
224     learn to talk slower or something like that don't you think,
225 P:  yesyes ((laughs)) that is what they learn but he they don't KNOW that I have
        dementia
226     and talk like that to me because of a sheet of paper (.) yesyes.
```

At the beginning of the segment (204/205), the interviewee emphasises that although "dementia" was on her referral from the family doctor, the latter does not know whether she really has dementia. She emphasises the word "know" (204) and agrees with the interviewer that it's an assumption (211) but explains the consequences immediately (213/214). From the emphasis on "know" (depicted in capital letters) one can derive that the contrast between 'knowing' and 'not knowing' is very important to the interviewee ('assuming' is introduced by the interviewer). The doctor's actions are perceived as irritating within this attitude. Later, after she had shared her experience about the receptionists who suddenly behaved quite differently (and visibly inexperienced) towards her due to the label "dementia" (217ff.), she returns again to the aspect that the doctor did 'not know' anything concrete about her health status (225) and that it is not okay to talk to her like this (she emphasises "so/like this") only because of a piece of paper (226) which underlines her distinction between knowing and not knowing/assuming again. Asking the question 'why' she points out consequences (actions of receptionists) and a responsible party (sheet of paper), one can consider that she describes the deterministic aspect of the situation she was put in.

In both studies, we found that the label 'at risk of developing psychosis/AD' plays an important role in the process of negotiating the entanglement between symptoms and personality, as well as the interrelation between labels for (naming), potential causes of (explaining), and ways of dealing with (coping) the condition of being 'at risk'. While the naming of risk can be experienced as a relief and a source of agency, it can also entail a perceived loss of control and feelings of being trapped in deterministic attributions.

Explaining

Current studies on physician-patient conversations in oncology show that physicians strongly concentrate on treatment, while pushing questions about the cause of disease into the background—even if patients repeatedly want to discuss the origin (Bentz et al., 2016; Imo, 2017). In our studies, the situation is different, because on the one hand there is no treatment and healing (AD) and on the other hand therapies are protracted and assumed to accompany persons for a lifetime (psychosis). The question of origin or source is therefore one of the most pressing concerns here. In the case of psychosis, our study shows that individuals' explanatory models of origin of the (risk of) disease consist of internal (undeserved—genetic; deserved—behavioural) and external (undeserved—family, social environment and life events) factors. Drug use can serve as a good example for these closely intertwined factors. On the one hand, drugs are seen as a risk factor for getting mentally ill and the experienced symptoms as a side effect of a certain lifestyle:

PSYP01 (Interviewee; study on psychosis)

And of course, especially when you start smoking grass, you get to grips with
the story, where it actually comes from and how it works and what THC actually is
and, um, then, in the course of that, you naturally also come across studies that …
talk about the increased risk of psychosis from long-term consumption and … (?)
Yes, and almost … (laughs) I smoked that for almost six years. Um … therefore …
Well, I knew the risks, but I didn't care about them.

On the other hand, drug use is perceived as a 'defence mechanism' and a way to regulate stress: Drugs play the role of 'a catalyst' that brings problems up to the surface early enough to make them obvious for oneself and the others, hereby accelerating the process of searching for help. This unavoidably raises questions of responsibility: "I have the feeling that I have ruined an area in my whole life!" (PSYP08). This feeling of guilt and responsibility has been an object of research in other clinical fields (e.g. the notion of 'genetic responsibility' in familial breast- and ovarian cancer—Etchegary et al., 2009, Hallowell, 1999). Here again, the tension between biomedical versus individual biographical explanations (Holmberg, Waters, Whitehouse, Daly, & McCaskill-Stevens, 2015) becomes obvious. For the researcher, this may imply being confronted with an expectation to provide an 'objective' opinion in the context of a narrative interview, for example, concerning the question of whether or not one is responsible for the condition of being 'at risk'.

Parallel to this notion, individuals attempt to 'normalise' this 'at risk'-condition by labelling the "awkward moments" and "crazy thoughts" as "normal" for each human being. The border between disease and health in this case is not marked by the fact that these crazy thoughts emerge but by the way of handling them. Our findings demonstrate that persons 'at risk' perceive the concept of risk in a fluid dimension, with the impossibility of defining a starting and an ending point.

PSYP04 (Interviewee; study on psychosis)

```
796  But also a thing I didn't think about at all before, so… so the basic attitude,
797  someday, you know? You can get any type of illness at some point, come down with
798  something, or somehow suffer from something. But so that, uh, there could actually be
799  something that somehow comes from the head and so without external influences, or
800  not. To say: Ok, you have this and that disease concretely, but that it is somehow
801  something that is not tangible.
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In our interviewees' narratives, we identified indications of how they construct meaning concerning their situation; for example, they described their risk as an inherent part of their biography. This reasoning was based on three sources of information: (1) risk prediction is based on symptoms which are perceived as an inherent part of the personality ("dreamy person" (PSYP03), "class clown" (PSYP01), "I grew up with it" (PSYP06), "I usually fantasize" (PSYP09), "I was always the weirdo" (PSYP10)) and thus a part of their 'normal' everyday condition; (2) prior experience with other therapies; and (3) intuition.

In our study on AD, the question of origin or source was not one of responsibility, even though behavioural risk factors have been described as well.[8] The risk is depicted much more deterministically ('the disease hits you') regardless whether the factors are internal or external. The essential way of dealing with the question of the origin culminates in considerations about heredity and detailed stories about family members with dementia. Some participants are quite sure that this will be their or their partner's "fate" (99), others hang on the hope "that the cup will pass them by" as the participant in AD02 (091, 098).

AD02 (Study on AD, baseline interview segment with an MCI patient)

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87 P:  yes MAYbe I am er (.) I am OLDer than my brothers and they are quite er demented;
88     one of them Max ((anonymised)) we always- with him I always went outside for a walk
89     but this is difficult now;
90 I:  why,
91 P:  yes he is quite er er: demented now and I hope that this cup will pass me by (--)
92     but you never er know -
93 I:  could you describe this feeling to me in a more detailed way?
94 P:  I REALLY have poor preconditions with our parents it was like that with my father
95     first and with my mother later but she wasn't so (.) so aggressive then-
96     but I am the third er the first but now the least ((laughs)) it doesn't always
97     hit everyone.
98     I hope like I said that the cup will pass me by but my wife says that it is the
99     family's fate (--) so far.
100    she also called ((the clinic)) and made the appointment.
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The process of 'explaining' in the case of risk for dementia due to AD sometimes even starts before the (new) 'naming' and may change in the course of the prediction procedures. Perceptions and explanations are different before and after predictive testing:

Before the predictive examination, two types of participants' perceptions were observed. Some pointed out that they are suffering from dementia, others that

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[8] Biomedical factors for dementia due to AD are also combined with modifiable risk factors, such as lifestyle-related factors (unhealthy diet, alcohol consumption, smoking, cognitive inactivity, physical inactivity and low education), cardiovascular risk diseases (diabetes, hypertension, obesity) and psychosocial factors (depression, social inactivity) (Livingston et al., 2017).

they are only ‘cognitively impaired’ and there is a strong possibility of remaining or improving beside the option of dementia (cf. Schwegler, Rostamzadeh, Jessen, Boada, & Woopen, 2017). Simultaneously, the latter explain duties or aspects from their everyday life to demonstrate how they are integrated, needed, and still perform well. For example, the interviewee (AD01) in a later segment points out that she could no longer take care of her mother if she had dementia herself. After the predictive examination, participants with two suspicious biomarkers (biomedical interpretation: 59% likelihood to develop dementia due to AD within the next three years) did not mention the possibility of remaining or improving anymore, but still narrate stories around their good performance to explain aspects of their capabilities to their interview partner.

In summary, our findings show that different attribution patterns are involved in the process of explaining one’s situation of being ‘at risk’. Relevant dimensions concerning the origin or source of one’s risk are related to questions of fate and guilt, internal or external causes, changes in explanatory models before and after risk testing and disclosure, as well as the endeavour to normalise one’s experiences and integrate them into one’s personal narratives. These different layers of interpretation are strongly intertwined with the individual’s perceived and enacted opportunities to cope with their condition.

Coping

The analysis of our interviewees’ accounts showed that the process of meaning-making (Park & Folkman, 1997) with respect to the at-risk state is closely related to individual coping mechanisms. The narratives reveal differences between persons at risk of psychosis and AD in terms of their coping strategies and also with regard to their experienced sense of agency and quality of life (QoL).

Coping in the context of risk for psychosis implies the notion of vulnerability in terms of keeping-up with everyday life on the one hand and reflecting on one’s individual illness prevention on the other hand. The notion of risk, the process of meaning-making and coping appear to be tightly entangled. The risk symptoms are perceived as a particularly strong and sophisticated warning and defence system enabling individuals to get control over the condition of imbalance. Risk is seen not as the enemy that should be controlled, but much more as a team player who can help to control the symptoms, and as a protective mechanism for mental health of each human being. As the quotations below exemplify, our interviewees’ narratives show the potential of meaning-making as a resource for (re-)constructing order instead of surrendering to disorder; for “achieving congruence between an individual’s global meaning and the appraised meaning of a particular event” (Park & Folkman, 1997, p. 116). Discussing risk with others is described as a strategy to understand and deal with it. At the same time, it should not be given “too much space” in order to keep the balance:

PSYP08 (Interviewee; study on psychosis)

As I've just explained, with me it's stress that causes the symptom to get worse. Well, I think it makes sense to know what's there, but it shouldn't be over-, uh, over-dramatized.

In contrast to the medical understanding of risk as a threat, our interviewees' accounts suggest that they also associate an idea of agency with risk, as the following quotation illustrates.

PSYP10 (Interviewee; study on psychosis)

That is, there is a very high risk of, um, getting schizophrenia or psychosis. Um. I know that in most cases it is determined by stress and diet, thus determined by life. If one lives a healthy life and avoids stress, then risk will in any case be lower.

The individuals in our study on AD are considered vulnerable because of their experienced and medically ascertained cognitive impairments (MCI diagnosed). Although they are still fully capable of shaping their everyday lives, they and their relatives noticed that they display cognitive difficulties. In addition to the risk, these individuals have to live with 'first symptoms' which they have to understand and evaluate for themselves. One understanding of risk (in combination with minor symptoms) is to implicitly go through and review the family history. Risk is strongly linked to heritability, and in a next step to subjective certainty of suffering from AD, combined with fear towards this condition. 'Being at risk for AD' basically does not trigger thoughts of consequentialist agency, but traps some persons in deterministic attributions and the search for explanations.

Overall, coping appears to be a process starting long before a risk disclosure following predictive testing. Due to interviews at two points in time (before/after predictive testing), our study on AD can shed light on different phases, variations and manifestations of this coping process in individuals with MCI symptoms and a risk for dementia due to AD:

Before the predictive testing some patients showed verbal self-distancing from the possible disease or diseased persons: From a linguistic point of view, it is very interesting that the interviewee in AD01 in her story (213–219) uses descriptive elements and deictic expression to distance herself both in terms of time and space from "those with dementia"/"them". This is in line with the attitude that dementia is just an assumption.

Directly following predictive testing, conspicuous test results can be shocking and unexpected as described in AD03 as "a punch back" (039) which led to a "breakdown" (042) and needed "time to digest" (045).

In the segment AD03, one can see from the progress of the conversational sequence that *normality can be restored within the narration*: The interviewee begins at a normality, which he summarises by himself as "everything was fine" (043). This normality was disturbed by the conspicuous test result. Afterwards, he establishes a 'new normality' by comparing himself with a 'truly diseased' person on the one and (average) persons at the same age on the other hand: "my father had it really badly, but with me, it is something totally different. What I have is normal for my age, but just, er, conspicious" (051–053).

After the predictive testing, in the light of first symptoms, some individuals developed a more 'conscious experiencing' of future actions regardless of a result with two, one or none suspicious biomarkers.

AD03 (Study on AD, 3-month follow-up interview segment with an MCI patient)

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032 I:  and then you came back in agAIn for the risk disclosure [right],
033 P:              [yes ].
034 I:  when the results were [THERE]-
035 P:                          [yes ]
036     er yes then the situation was a LITtle different.
037 I:  mhm;
038 P:  the professor was with us (.) huh,
039     and er this and that (-) and this and that was (.) of course a punch back (-)
040     er (---) but told me again YES oKAY but within a small er rANge
041     that one can do something or something IS to do if something happens -
042     an there I was inside I won't say broke down this would be OVERstated.
043     but damn it, that CAN't be (-) so far they told me everything was fine and it gets
044     better and then they told me so to say unconcerned nevertheless we found something;
045     then I needed some amount of time to digest that;
046 I:  and now,
047 P:  yes er basically like always;
048     before some days were good some were bad,
049     that is so to say normal in my age if I may put it this way (-)
050     I am continuing normally now.
051     my father so to say had it badly (-) really badly,
052     but with me (-) it is something totally different.
053     what I have is normal for my age (-) but just er conspicuous.
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As this section illustrates, the interview can be a space for the negotiation of questions about self-perception, self-awareness, agency and determinism, as well as for the narrative restoring of (a new) normality.[9]

Methodological Reflection: Negotiating Vulnerability and Normality

Throughout the research process, by means of reflexivity, we aimed at creating a space for re-defining the power of definition, including notions of vulnerability and normality, with regard to risk. In the following, we will discuss central methodological issues that emerged in the course of our studies. These include the planning and preparation of the study, the sampling strategy, the interview process, roles and responsibilities between researcher and interviewee, ethical considerations, as well as data analysis and interpretation. Our reflections aim at providing insights into

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[9] Alongside to the role of meaning-making, the interrelation between coping with risk and QoL became visible in both projects during data analysis. For example, the episodic interviews in our study on AD provided us with the opportunity to capture differences between individual descriptions of QoL (in the narrative part), concrete specifications (from the semantic part), and a 'scientific' understanding used in common definitions of QoL (c.f. Rostamzadeh et al., in press; Woopen, 2014).

opportunities and challenges related to the practice of doing research on risk in mental health.

Ethical Considerations Concerning the Notion of 'Vulnerability'

In the process of designing the research, we classified the condition of being considered as a person 'at risk' as vulnerable. This had implications for our ideas of the appropriate way to encounter our study participants during the interview situation, and for our assumptions about the impact of risk on their lives.[10] But which impact does this vulnerable condition have on the research process and the interview topics, and how can the researcher handle it?

Although the narrative interviews were conducted based on a flexible topic guide and open dialogue, the potential distress caused by certain individual topics was a central concern in the research process. It is true that in an open research format, informants determine themselves, based on their own relevance criteria, which aspects of risk experience and understanding of health and disease are in focus. This however does not exclude the possibility that sensitive, stressful or traumatic experiences may be brought up in the course of the interview. For the interviewees, this could mean a danger of being confronted with these experiences again and of overemphasising their 'vulnerable condition at risk' or their 'patient role' through the narration. We therefore took precautionary measures to avoid additional stress for the research participants presumably caused by the narrative interview. At the outset of the study, thorough reflections on the balance between potential benefit and harm for study participants were made in the context of applying for ethics approval. During the interview, we made continuous careful considerations, weighing our curiosity as researchers and the wish to attain as much information as possible against the fear of undue confrontation and intrusion, and the wish to protect the interviewees from distress. At the end of the interview, we offered our participants the opportunity to give us a signal of stress or unpleasant feelings, using a feedback form they could return to us in a sealed envelope. In some cases, we made a follow-up telephone call or emailed participants when we had the impression that the interview may have left them behind too agitated. Overall, our participants described their experience of the interview situation as comfortable and caring; however, it could also be perceived as a distressing situation. Some of them described it as pleasant to talk to someone unknown who is not a family member or their physician, or they reported that it had been interesting and helpful for them to reflect on their situation during the narrative interview. This is in line with observations by other authors about the potential of the narrative interview as an 'identity-forming action or discursive production of the self' (Lucius-Hoene, 2002, p. 178) that may even have a healing effect (Rosenthal,

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[10] After considering risks and benefits for the informants, as a first step, the research team developed a guideline for the conduct of the interviews, for the process of pseudonymisation and for the publication of the results according to the "principle of non-harm" (Hopf, 2005).

1995). Since there is no guarantee for this positive effect, we nevertheless directed our efforts at avoiding stress and possible harm.

In the course of the interviews for this study, it became obvious that the topic of family is one of the most sensitive when doing qualitative research in this clinical field. A major question was how to ask about family without aggravating this vulnerable condition?

In spite of various discussions and researcher self-reflection, we cannot offer a general solution. After analysing the data, we realised that each researcher's decision whether to ask further questions or not and when to change the topic was based on 'inner feeling'. The choice is based on an ethical judgement that researchers will need to make for themselves, and preferably discuss with colleagues in the team, or use other spaces for reflection such as intervision or research workshops.

Qualitative Research in a Medically Oriented Scientific Environment

In the process of research conceptualisation, our teams faced the challenge of two fundamentally different approaches in the way of designing the research process. In a medically oriented environment, operationalisation of research questions is expected to follow a standardised approach based on predetermined definitions of risk and QoL. This confronted us with conflicting ideas about the appropriate sampling strategy or the suitable ways of collecting data.

As a compromise, concerning the criteria for in- and exclusion of participants, we agreed on medically defined criteria of 'persons at risk' of developing psychosis or AD.[11] This decision requires a further methodological reflection on our sampling strategy. Defining biomedical inclusion and exclusion criteria is an attempt to objectify individuals' intuitive feeling of risk and automatically excludes persons who feel at risk without having a biomedical explanation of this feeling. This strategy should be critically reconsidered in future studies. A possible solution is to circumvent the strict—and temporary—medical criteria by including an additional criterion of 'feeling at risk'. The recruiting process could take place both in cooperation with the medical prediction centres and randomly with the help of adverts or announcements. Concerning the operationalisation of research questions, we encountered challenges in terms of the degree of openness and standardisation in approaching concepts of interest such as risk or quality of life (QoL). Our studies aimed at an open, discovery-oriented approach providing a bottom-up perspective in order to generate a definition grounded in empirical data. In our study on psychosis, the iterative process alternating between data collection and analysis (Palinkas, 2014) offered a fruitful ground for several transformations related to the research setting, methodology and research relationship between interviewer and interviewee. However, such an approach meets resistance and requires methodological negotiation in a primarily medically oriented research environment.

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[11] The only individuals who can currently obtain a predictive test in clinical practice are patients (medically) as MCI.

We also realised how different methodologies can result in divergent findings on a seemingly consensual concept such as QoL. In our study on AD, the overall focus of the mixed methods approach (cf. Box 1) was on the effect of risk prediction on the QoL of persons at risk and their family members. We aimed at contrasting the findings of the common and established standardised questionnaires on QoL, satisfaction with/in life and well-being with the findings of the qualitative approach: Within the narrative parts of the episodic interviews—in which we explicitly avoided terms such as QoL, satisfaction or well-being—together with the semantic part of the interview—in which we explicitly asked for subjective specifications of those terms—we were able to shed light on the subjective descriptions of the semantic field of QoL and related concepts such as well-being and risk. This can lead to a reasonable appraisal of the individual meanings of QoL and may hence help to strengthen the appreciation of the qualitative approach in relation to the quantitative data. Interestingly, the analysis of the subjective definitions revealed that the concrete expression 'quality of life' is mostly understood in monetary terms ("to have enough money to life a good life"), while the expressions 'well-being'/'satisfaction' might be better terms in everyday language to represent the health-related understanding of 'having a good life'.

Hence, in a medically oriented scientific environment, researchers need to face the blurred borderline between objectivism and subjectivism, general and specific, fact and interpretation in the context of qualitative research in mental health.

Data Generation—Asking About Risk

Concerning the assumed impact of risk on people's lives, our strategy of mitigating harm and bias included a reserved attitude towards the label of 'being at risk' and avoiding the use of this wording in the beginning phase of the interview. In both of our studies, the medical understanding of risk is presented to our participants during their clinical diagnostics and treatment, but the understanding of risk in both instances differs. In order to bridge this definitional gap, we decided not to employ a single or fixed definition of risk, but "to elicit the perspective of those being studied" (Sofaer, 1999, p. 1105). We used conversation techniques that minimise the use of 'objective definitions' of risk, and the emphasis on 'medical knowledge'. Throughout the interviews, we regularly explored the background of the narratives ("How do you know about that?" and "Could you explain your feelings and thoughts (in this specific situation)?") in order to create a space for individual frameworks of meaning, including the verbalisation of somatic (bodily) knowledge (Samerski, 2019).

While conducting the interviews and analysing the data, we realised that even if we agreed on a short and clear opening question, it had been slightly modified in each interview depending on the pre-conversation and the conversation atmosphere. This reveals on the one hand the researchers' own personal attitude towards the label 'being at risk of developing psychosis/AD' and on the other hand the ethical concerns related to the interview situation; the danger of introducing a label or a meaning of 'risk' that may be not relevant for the individual's life.

The Interview as a Setting and Format for Data Generation on Mental Health Risk

Our data analysis allowed for a methodological reflection on the interview as an appropriate setting for generating meaningful information. In the context of mental health, especially within our study on psychosis, we often meet interview-partners who have experience with conversations that aim at generating narratives (in the context of previous therapies or psychological conversations with professionals). The high ability of self-reflection among the interview-partners enabled a highly differentiated approach to the self and the disease, offering expert knowledge on symptoms, risk and individuals' daily struggles. From a researcher point of view, this should be considered as an important factor which influences the type of the collected data and poses challenges to their interpretation.

A further important task was to discover the different voices narrating the story. Narrative interviews in the context of mental health 'at risk' contain a great share of self-interpretation, narratives on psychological interpretations and external definitions. Additional data sources such as field notes and memos can be fruitful to enrich and complete the verbal way of telling about perceptions. These additional means of data collection require an increased awareness of the researcher's role in conducting the interview as well as control over the dynamics of proximity and distance during the interview. A look into the data reveals some of the researcher's strategies to stay "open" (DeWalt & DeWalt, 1998) and curious, keeping their attention independent from medical background information or therapeutic experience: emphasising empathy ("I can imagine how difficult this situation was"), personal disclosure, appreciation ("that's exciting") and re-questioning one's own question ("this question may not be so relevant, but I am curious to know").[12]

Negotiating Roles and Responsibilities in the Research Process

Our findings and memos reveal that the process of role definition during the interview was an issue from the interviewees' point of view. This became visible through discussions on the research questions ("Do you follow a specific common thread while asking these questions?" (PSYP01)), evaluations on the notion of representativeness of the project results ("I am wondering if what I say could be representative for others?" (PSYP02)), thematising their own role as a research participant ("Am I a patient, or a client, or what is the right term here?" (PSYP01)).

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[12] An additional aspect that invites further analysis and reflection is the gender dimension of the research. All researchers are female and of different ages. Both gender and age certainly have an impact on the interview dynamics but due to space limitation, these aspects will not be further discussed in this contribution.

This ‘patient-role’ became visible in different stages in the course of the interview. Research participants adopted medical language not only when describing different diagnoses and symptoms, but also when reflecting on their coping strategies, everyday feelings and experiences and interactions with others. Apart from this adoption of terminology, role definition in general was not a very obvious, but still a constantly present issue in the interview process. We noticed interviewees switching between the role of the patient (having experience with diagnoses and therapies), the self-reflected and aware person (emphasising one’s own importance in the process of managing mental health) and the knowledgeable person, “cognisant of researchers and doctors” (highlighting one’s own position as an experienced person in communication with doctors and researchers). This helped us as researchers to minimise the risk of reducing the interviewees to their traumatic experience, or to exclude areas or phases of their lives that may be relevant to the research question (Loch & Rosenthal, 2002). On our part, we as researchers also took measures to minimise these risks, such as the use of questioning techniques for in-depth exploration, in some instances self-disclosure, scheduling sufficient time and space, re-establishing contact after the interview (Küsters, 2009), and a process-accompanying self-reflection among the research team.

Summary: Methodological Reflection and Research Ethics

The following questions (Box 2) are intended as a source for reflection, rather than guidelines or rules, when planning and conducting a qualitative study on mental health risk. The leading idea is to encourage considering the methodological decisions at each stage throughout the research process in terms of their implications for the data that will be generated. Eventually, methodological reflection on these issues may contribute to constructively dealing with the tension between a standardised biomedical and an open, bottom-up approach in a medically oriented scientific environment.

Box 2: Questions for reflection

Ethical considerations concerning the notion of ‘vulnerability’	
Sensitive topics /traumatic experiences	Are there issues of responsibility or feelings of guilt related to the condition of being at risk (e.g. in terms of the interviewee’s behaviour, implications of his/her situation for close others, or heredity)? If yes, what may the methodology of qualitative enquiry imply in terms of a confrontation with these feelings guilt? How can the researcher prepare for situations surrounding potential feelings of guilt in conversations with the interviewee? For example, the researcher may need to be prepared for being asked about his or her opinion about appropriate ways of dealing with the risk or about questions of responsibility; or he/she may need to make a trade-off between curiosity and the wish to protect the interviewee from potential harm by overly intrusive questions

(continued)

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Qualitative research in a medically oriented environment	
Research design	In an interdisciplinary, medically oriented research environment, qualitative researchers will be challenged to make a trade-off between the demands of an open, circular research process guided by the premises of theoretical sampling and data saturation, and the expectations of an a priori elaborated, standardised, and linear research procedure usually expected in the medical field
Sampling	With regard to mental health risk, careful considerations are required concerning the operationalisation of the 'condition at risk'. How are risk factors defined according to the current state of knowledge? Do medical guidelines on risk detection differ from discourses in the media? What do people think about their own risk? Based on our experience, we recommend scheduling time during the study preparation for detailed discussion with clinicians, but also with participants, about risk factors, different risk constellations, and in- and exclusion criteria for study participation. Recruiting interviewees could take place both in collaboration with medical prediction centres and using adverts or announcements
Data generation—asking about risk	
Using the term 'risk'	'Risk' may have a variety of meanings and implications, not only with respect to different mental health conditions, but also for different people and in different socio-biographical contexts. We therefore encourage researchers to reflect on the implications of when and how to introduce the term risk in the research process, including the first contact with the interview partners and the opening question of the interview. The choices will also depend on the recruitment process and on the procedures of clinical prediction and risk communication (for example, whether disclosure of the clinical high risk has already occurred and if yes, in which way, and how long ago)
The interview as a method of data collection	Researchers are encouraged to reflect on the choice of an interview as a setting and format for data generation on mental health risk. This is of particular importance when talking to persons familiar with a high degree of self-reflection, for example when experienced in psychotherapy. With regard to research on mental health risk, different knowledge systems come into play; these will also be reflected in the interviewees' narratives. Different stocks of knowledge may inform their reflections, for example normative ideas about their condition, adopted medical language and expert knowledge, or concerns uttered by family and friends. We therefore encourage researchers to stay alert concerning the different voices 'speaking' in the interviewees' narratives. In addition, other methods of data collection may be considered, allowing for non-verbal data generation
Negotiating roles and responsibilities in the research process	

(continued)

(continued)

Between disorder and normality	The condition of being 'at risk' for a mental health problem introduces the negotiation between disorder and normality. We argue that both the interviewee and the researcher will locate themselves somewhere on the continuum between these two poles. As a researcher, one needs to engage in the reflection about how to deal with his/her own 'mental vulnerability', and will be required to reconsider this position in relation to different interview partners. This includes choices such as 'Will it be appropriate to employ self-disclosure in support of a trusting relationship with the interviewee?' or 'Which personal memories, threats or anxieties may the interview trigger in me as a researcher?'
Data analysis	
Tools and sources for reflection	When analysing data, it is important to keep in mind that narratives generated through qualitative enquiry are the result of a co-construction between researcher and interviewee. We therefore encourage researchers to employ diverse tools and sources for reflexivity, such as auto-ethnographic memos or thick descriptions following the interview, metadata-protocols, and discussions in the interdisciplinary research team. Herein, researchers can use questions such as 'What are my own thoughts, fears, and prejudice concerning the risk in question?'; 'Which implications do my assumptions have for the topics addressed in the interview, and for those neglected or hidden?'

Conclusion: Methodologies in Support of Reclaiming Power

Qualitative methodologies are a powerful way for people experiencing mental distress to speak for themselves. We argue that they can constitute a valid approach to understanding people's experiences and perspectives in mental health care as well as in mental health research (Powell, Single, & Lloyd, 1996). In the two studies presented in this chapter, we drew on approaches from linguistics and medical ethnology, and we used narrative methodology and reflexivity in order to open up definitional spaces between researchers and interviewees. A reflection on both the content and the process of the interviews conducted during both studies allows for some considerations concerning the power of definition. Constantly taking a step back and questioning our strategies and interpretations before, during and after the interviews provided the opportunity for re-defining concepts related to the notion of being 'at risk' for psychosis or dementia, such as vulnerability, QoL, and risk itself. The narrative and episodic interviews proved to be a fruitful source for the discursive generation of definitions, unfolding the multi-faceted understandings of health. It became evident that risk, beyond 'objective' scores and percentages, can have divergent meanings to different persons and in the context of different health conditions such as psychosis or Alzheimer's dementia. Risk is a mediator at the border between order and disorder; beyond being perceived as a threat, risk can also be a regulator in the process of negotiating normality. Persons being confronted with a health risk can (re)gain agency by either interpreting their risk as a source for self-awareness and self-care, or by trying to restore order and normality through their narrations.

Methodologically, our studies revealed particular opportunities but also challenges concerning the realisation of a qualitative approach in the context of a medically oriented environment. For example, our sampling strategies were shaped by the medically defined risk factors for psychosis and dementia, and methodological negotiations with our clinical partners were needed to convey the benefit of a discovery-oriented—rather than a standardised—approach to concepts such as risk or QoL. We also reflected on the interview as an appropriate format of generating meaningful knowledge, particularly among persons who are familiar with a high level of self-reflection, or with a view to different ‘voices’ speaking in the narratives, such as personal interpretations, but also knowledge and beliefs adopted from physicians, family, or the media. In the future, an even more open-ended and spirited approach to sampling and data collection may be worthwhile, for example, by including self-definitions of ‘at-risk’ states, or by employing pre-discursive forms of data collection such as in arts-based research.

In terms of disciplinary approaches, instead of being restricted even more by biomedical thinking, dementia and mental health research ought to refocus on a variety of disciplines such as sociology, anthropology, philosophy, or politics (Timimi, 2014) in order to accommodate a broader understanding of the person and their well-being. Biomedical, psychosocial, and cultural models of mental health should be appropriately balanced in order to do justice to a holistic perspective on mental health (Puras, 2017). In particular, user-lead research has the potential to overcome power asymmetries characteristic of biomedical study designs, and to be able to ‘cut to the heart of issues that are important to service users themselves’ (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007, p. 60). Stories and storytelling can be considered as the heart of qualitative methodology, particularly in narrative, linguistic and ethnographic approaches. As a particular example, auto-ethnography can be a fruitful methodology, capable of generating dense accounts of a person’s lived experiences by connecting these to cultural process and understanding (Liggins, Kearns, & Adams, 2013; see also Willig in this book).

In conclusion, when awarding people the opportunity to speak for themselves in the context of mental health research, their personal accounts and narratives can help challenge existing social constructions of their conditions. This can also allow for new perspectives on the experiences of people living with mental distress (Zeilig, 2014; Zimmermann, 2017). The narrative approach offers the potential to (re)arrange life events and experiences, and to attribute subjective meaning to their condition, which can be an important resource for coping with the at-risk state. Moreover, narratives allow for accommodating different forms and types of health knowledge, including intuition and somatic (bodily) knowledge. From a sociology of knowledge perspective, qualitative research can therefore offer the opportunity to contribute to new realities of mental health in terms of scientific knowledge production, diagnostics and treatment, as well as personal and public perception. Eventually, qualitative approaches to data collection, analysis, and interpretation open up spaces for reclaiming power concerning the experience, the definition, and the appraisal of mental health.

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Literature

Albert, M. S., DeKosky S. T., Dickson, D., Dubois, B., Feldman, H. H., Fox, N. C., … Phelps, C. H. (2011). The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dementia, 7*(3), 270–279. http://doi.org/10.1016/j.jalz.2011.03.008.

Aronowitz, R. A. (2009). The converged experience of risk and disease. *The Milbank Quarterly, 87*(2), 417–442. https://doi.org/10.1111/j.1468-0009.2009.00563.x.

Bearden, C. E., & Forsyth, J. K. (2018). The many roads to psychosis: Recent advances in understanding risk and mechanisms. *F1000Research*, 7 (F1000 Faculty Rev), 1883. https://doi.org/10.12688/f1000research.16574.1.

Bentz, M. Binnenhei, M., Coussios, G., Gruden, J., Imo W., Korte, L., … Stier, S. (2016). Von der Pathologie zum Patienten: Optimierung von Wissenstransfer und Verstehenssicherung in der medizinischen Kommunikation. *Sprache und Interaktion, 72,* 1–43.

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. Doubleday: New York.

Birkner, K. (2006). Subjektive Krankheitstheorien im Gespräch. *Gesprächsforschung, 7,* 152–183.

Breuer, F., Muckel, P., & Dieris, B. (2019). *Reflexive grounded theory: Eine Einführung für die Forschungspraxis* (4th ed.). Wiesbaden: Springer VS.

Byrne, R., & Morrison, A. P. (2010). Young people at risk of psychosis: A user-led exploration of interpersonal relationships and communication of psychological difficulties. *Early Intervention in Psychiatry, 4*(2), 162–168. https://doi.org/10.1111/j.1751-7893.2010.00171.x.

Clarke, A. E., Shim, J. K., Mamo, L., Fosket, J. R., & Fishman, J. R. (2003). Biomedicalization: technoscientific transformations of health, illness, and U.S. biomedicine. *American Sociological Review, 68*(2), 161–194. https://doi.org/10.2307/1519765.

Denzin, N. (1970). *The research act in sociology*. London: Butterworth.

Deppermann, A. (2008). *Gespräche analysieren: Eine Einführung* (5th ed.). Wiesbaden: Springer VS.

Deppermann, A. (2013). Interview als text vs. interview als interaktion. *FQS Forum Qualitative Sozialforschung, 14*(3), 1–36.

DeWalt, K. M., & DeWalt, B. R. (1998). Participant observation. In B. H. Russell (Ed.), *Handbook of methods in cultural anthropology* (pp. 259–300). Walnut Creek: AltaMira Press.

Ermine, W., Sinclair, R., & Jeffery, B. (2004). *The ethics of research involving indigenous peoples: Report of the indigenous People's Health Research Centre to the Interagency Advisory Panel on Research Ethics*. Saskatoon (SK): Indigenous People's Health Research Centre.

Etchegary, H., Miller, F., deLaat, S., Wilson, B., Carroll, J., & Cappelli, M. (2009). Decision-making about inherited cancer risk: Exploring dimensions of genetic responsibility. *Journal of genetic counseling, 18*(3), 252–264. https://doi.org/10.1007/s10897-009-9218-z.

Fleck, L. (1979). *Genesis and development of a scientific fact.* Chicago: University of Chicago Press.

Flemming, I. M. (2010). Ethnography and ethnology. In H. J. Birx (Ed.), *21st century anthropology: A reference handbook*. Thousand Oaks: Sage.

Flick, U. (1997). *The episodic interview: Small scale narratives as approach to relevant experiences* (Discussion Papers—Qualitative Series). http://docshare01.docshare.tips/files/24191/241911951.pdf.

Frances, A. (2014). *Normal. Gegen die Inflation psychiatrischer Diagnosen.* Köln: DuMont.

Fusar-Poli, P. (2017). The clinical high-risk state for psychosis (CHR-P), Version II. *Schizophrenia Bulletin, 43*(1), 44–47. https://doi.org/10.1093/schbul/sbw158.

Geertz, C. (1973). Thick description: Towards an interpretive theory of culture. In C. Geertz (Ed.), *The interpretation of cultures* (pp. 3–32). New York: Basic Books.

Gigerenzer, G., Gaissmaier, W., Kurz-Milcke, E., Schwartz, L. M., & Woloshin, S. (2007). Helping doctors and patients make sense of health statistics. *Psychological Science in the Public Interest, 8*(2), 53–96. https://doi.org/10.1111/j.1539-6053.2008.00033.x.

Gillespie, C. (2012). The experience of risk as 'measured vulnerability': Health screening and lay uses of numerical risk. *Sociology of Health and Illness, 34*(2), 194–207. https://doi.org/10.1111/j.1467-9566.2011.01381.x.

Goodenough, W. H. (1956). Residence rules. *Southwestern Journal of Anthropology, 12*(1), 22–37.

Groleau, D., Young, A., & Kirmayer, J. (2006). The McGill illness narrative interview (MINI): An interview schedule to elicit meanings and modes of reasoning related to illness experience. *Transcultural Psychiatry, 43*(4), 671–691. https://doi.org/10.1177/1363461506070796.

Gronemeyer, R. (2013). *Das 4. Lebensalter. Demenz ist keine Krankheit*. München: Pattloch.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? *Field Methods, 18*(1), 59–82. https://doi.org/10.1177/1525822x05279903.

Hallowell, N. (1999). Doing the right thing: Genetic risk and responsibility. *Sociology of Health & Illness, 21*(5), 597–621.

Holmberg, C., Waters, E. A., Whitehouse, K., Daly, M., & McCaskill-Stevens, W. (2015). My lived experiences are more important than your probabilities: The role of individualized risk estimates for decision making about participation in the study of Tamoxifen and Raloxifene (STAR). *Medical Decision Making: An International Journal of the Society for Medical Decision Making, 35*(8), 1010–1022. https://doi.org/10.1177/0272989X15594382.

Hopf, C. (2005). Forschungsethik und qualitative Forschung. In U. Flick, E. von Kardorff, & I. Steinke (Eds.), *Qualitative Forschung. Ein Handbuch* (pp. 589–599). Reinbek bei Hamburg: Rowohlt.

Imo, W. (2017). Trösten: Eine sprachliche Praktik in der Medizin. *Muttersprache, 3*(17), 197–225.

Jack, C. R., Bennett, D. A., Blennkow, K., Carrillo, M. C., Dunn, B., Haeberlein, S. B., … Sperling, R. (2018). NIA-AA research framework: Toward a biological definition of Alzheimer's disease. *Alzheimer's Dementia, 14*(4), 535–562. http://doi.org/10.1016/j.jalz.2018.02.018.

Jessen, F., Amariglio, R. E., van Boxtel, M., Breteler, M., Ceccaldi, M., Chételat, G., … Wagner, M. (2014). A conceptual framework for research on subjective cognitive decline in preclinical Alzheimer's disease. *Alzheimer's Dementia, 10*(6), 844–852. http://doi.org/10.1016/j.jalz.2014.01.001.

Keller, R. (2011). The sociology of knowledge approach to discourse (SKAD). *Human Studies, 34,* 43–65.

Küsters, I. (2009). *Narrative Interviews: Grundlagen und Anwendungen* (2nd ed.). Wiesbaden: Springer VS.

Largent, E. A., & Karlawish, J. (2019). Preclinical Alzheimer disease and the dawn of the pre-caregiver. *JAMA Neurology, 76*(6), 631–632. https://doi.org/10.1001/jamaneurol.2019.0165.

Liggins, J., Kearns, R. A., & Adams, P. J. (2013). Using autoethnography to reclaim the 'place of healing' in mental health care. *Social Science and Medicine, 91,* 105–109. https://doi.org/10.1016/j.socscimed.2012.06.013.

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., … Mukadam. N. (2017). Dementia prevention, intervention, and care. *Lancet*, *390*(10113), 2673–2734. http://doi.org/10.1016/S0140-6736(17)31363-6.

Loch, U., & Rosenthal, G. (2002). Das narrative interview. In D. Schaeffer & G. Müller-Mundt (Eds.), *Qualitative Gesundheits- und Pflegeforschung* (pp. 221–232). Bern u. a.: Hans Huber.

Lucius-Hoene, G. (2002). Narrative Bewältigung von Krankheit und Coping-Forschung: Psychotherapie und Sozialwissenschaften. *Zeitschrift für qualitative Forschung, 4*(3), 166–203.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews [63 paragraphs]. *Forum: Qualitative Social Research, 11*(3), Art. 8. https://doi.org/10.17169/fqs-11.3.1428.

Mitchell, A. J., & Shiri-Feshki, M. (2009). Rate of progression of mild cognitive impairment to dementia: Meta-analysis of 41 robust inception cohort studies. *Acta Psychiatrica Scandinavica, 119*(4), 252–265. https://doi.org/10.1111/j.1600-0447.2008.01326.x.

Nohl, A. (2017). *Interview und Dokumentarische Methode*, 3–13. https://doi.org/10.1007/978-3-658-16080-7_1.

Palinkas, L. A. (2014). Qualitative and mixed methods in mental health services and implementation research. *Journal of Clinical Child & Adolescent Psychology, 43*(6), 851–861. https://doi.org/10.1080/15374416.2014.910791.

Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology, 30,* 115–144.

Pellegrino, E. D. (1992). Intersections of western biomedical ethics and world culture: Problematic and possibility. *Cambridge Quarterly of Healthcare Ethics, 1*(3), 191–196. https://doi.org/10.1017/s0963180100000360.

Pitt, L., Kilbride, M., Nothard, S., Welford, M., & Morrison, A. P. (2007). Researching recovery from psychosis: A user-led project. *Psychiatric Bulletin, 31*(2), 55–60. https://doi.org/10.1192/pb.bp.105.008532.

Powell, R. A., Single, H. M., & Lloyd, K. R. (1996). Focus groups in mental health research: Enhancing the validity of user and provider questionnaires. *International Journal of Social Psychiatry, 42*(3), 193–206.

Puras, P. (2017). Human rights and the practice of medicine. *Public Health Reviews, 38*(9). https://doi.org/10.1186/s40985-017-0054-7.

Reichertz, J. (2015). The meaning of researchers' subjectivity. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *16*(3). Article number 33. https://doi.org/10.17169/fqs-16.3.2461.

Rosenthal, G. (1995). *Erlebte und erzählte Lebensgeschichte. Gestalt und Struktur biographischer Selbstbeschreibungen.* Frankfurt/Main: Campus.

Rostamzadeh, A., Schwegler, C., Gil, S., Romotzky, V., Ortega, G., Canabate, P., … Woopen, C. (in press). Biomarker-based risk prediction of Alzheimer's dementia in MCI: Psychosocial, ethical and legal aspects—the PreDADQoL project. *JAD Journal of Alzheimer's Disease, 2021.*

Sachs-Jeantet, C., Sagasti, F. R., & Salomon, J. J. (1994). *The uncertain quest: Science, technology, and development*. Tokyo: United Nations University Press.

Samerski, S. (2013). Professioneller Entscheidungsunterricht: Vom Klienten zum mündigen Entscheider. *Leviathan, 41*(1), 144–163. https://doi.org/10.5771/0340-0425-2013-1-144.

Samerski, S. (2019). Health literacy as a social practice: Social and empirical dimensions of knowledge on health and healthcare. *Social Science and Medicine, 226,* 1–8. https://doi.org/10.1016/j.socscimed.2019.02.024.

Schaarschmidt, T. (2018, January 2). *Ich bin nicht verrückt, ich bin Revoluzzer* [online newspaper article]. Retrieved from https://www.zeit.de/wissen/gesundheit/2018-01/antipsychiatrie-psychiatrien-psychologie-patienten. Accessed 14 Apr 2019.

Schultze-Lutter, F., Schmidt, S. J., & Theodoridou, A. (2018). Psychopathology: A precision tool in need of re-sharpening. *Frontiers in Psychiatry, 9*(446). https://doi.org/10.3389/fpsyt.2018.00446.

Schütze, F. (1983). Biographieforschung und narratives Interview. *Neue Praxis, 3*(13), 283–293.

Schwegler, C., Rostamzadeh, A., Jessen, F., Boada, M., & Woopen, C. (2017). Expectations of patients with MCI and their caregivers towards predictive diagnosis of AD: A qualitative approach. *Alzheimer's and Dementia, 13*(7), 538. https://doi.org/10.1016/j.jalz.2017.06.641.

Selting, M., Auer, P., Barth-Weingarten, D., Bergmann, J. R., Bergmann, P., Birkner, K., … Hartung, M. (2009). Gesprächsanalytisches Transkriptionssystem 2 (GAT 2*). Ge-sprächsforschung –Online-Zeitschrift zur verbalen Interaktion, 10,* 353–402.

Smith, L. T. (2012). *Decolonizing methodologies: Research and indigenous peoples* (2nd ed.). London and New York: Zed Books.

Sofaer, S. (1999). Qualitative methods: What are they and why use them? *Health Services Research, 34*(52), 1101–1118.

Sykes, S., Wills, J., Rowlands, G., & Popple, K. (2013). Understanding critical health literacy: A concept analysis. *BMC Public Health, 13*(150). https://doi.org/10.1186/1471-2458-13-150.

Timimi, S. (2014). No more psychiatric labels: Why formal psychiatric diagnostic systems should be abolished. *International Journal of Clinical and Health Psychology, 14*(3), 208–215. https://doi.org/10.1016/j.ijchp.2014.03.004.

Vos, S. J. B., Verhey, F., Frölich, L., Kornhuber, J., Wiltfang, J., Maier, W., … Visser, P. J. (2015). Prevalence and prognosis of Alzheimer's disease at the mild cognitive impairment stage. *Brain, 138*(5), 1327–1338. http://doi.org/10.1093/brain/awv029.

Wakefield, J. C. (2012). Der Begriff der psychischen Störung: An der Grenze zwischen biologischen Tatsachen und gesellschaftlichen Werten. In T. Schramme (Ed.), *Krankheitstheorien*. Berlin: Suhrkamp.

Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In H. Cooper (Ed.), *The handbook of research methods in psychology*. Washington, DC: American Psychological Association.

Woopen, C. (2014). Die Bedeutung von Lebensqualität aus ethischer Perspektive [The significance of quality of life – an ethical approach]. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 108*(2–3), 140–145. https://doi.org/10.1016/j.zefq.2014.03.002.

Zeilig, H. (2014). Dementia as a cultural metaphor. *The Gerontologist, 54*(2), 258–267. https://doi.org/10.1093/geront/gns203.

Zimmermann, M. (2017). Alzheimer's disease metaphors as mirror and lens to the stigma of dementia. *Literature and Medicine, 35*(1), 71–97. https://doi.org/10.1353/lm.2017.0003.

2.3.3 CULTURE AND GENETICS: CRITICAL HEALTH LITERACY AND RISK PREDICTION

Article 3: Lorke, Mariya*; Harzheim, Laura; Rhiem, Kerstin; Woopen, Christiane; Jünger, Saskia (2021): The ticking time-bomb. Health Literacy In The Context Of Genetic Risk Prediction In Familial Breast-Ovarian Cancer. A Qualitative Study. In: *Qualitative Research in Medicine & Healthcare* 5. DOI: 10.4081/qrmh.2021.9647.

The third contribution addresses the concept of risk as the genetic risk of developing familial breast and ovarian cancer. This article illuminates the challenges for a person's understanding and critical appraisal of risk-related information, as well as for their decision-making after getting a positive result from genetic testing. This contribution anchors the concept of health literacy in qualitative empirical data, enriching the primarily quantitative top-down approach which is mostly led by specialist-driven definitions.

The article mirrors a qualitative study design and integrates an ethnographic-narrative approach. The contribution is based on 10 narrative interviews with women who have undergone genetic testing for familial breast and ovarian cancer. The interviews were conducted from 07/2018 to 10/2018, audio-recorded and transcribed. The data were analysed using Reflexive Grounded Theory.

The findings allow for insights into different levels of knowing about, perceiving and dealing with an increased risk of developing familial breast and ovarian cancer. Grounded in the individuals' description of their risk perceptions, the narratives reveal the entanglement of the women's risk of getting ill, their identity and their strategies for managing health. The analysis of this interplay provides multiple starting points of approaching health literacy in its communicative dimension and addresses the concept of reflexivity in the context of critical health literacy. The findings suggest that current conceptualisations of health literacy and its sub-dimensions do not always correspond to the understanding and perceptions of the persons at risk themselves.

In the context of the overarching research question of this thesis, this article speaks for differences between the culture of risk understanding in biomedicine, and that of advice seekers. Even when talking about medically driven concepts such as genetic risk, a culture-sensitive approach to health literacy in science, medical practice and research is needed. Putting the individual at the centre of inquiry, with his or her particular health knowledge, competences, and strategies – as in the case of intercultural communication – may be a way of promoting health literacy among individuals and organisations, and of supporting the process of negotiating threat and confidence.

The ticking time-bomb. Health literacy in the context of genetic risk prediction in familial breast-ovarian cancer; A qualitative study

Mariya Lorke,[1] Laura Harzheim,[1] Kerstin Rhiem,[2]
Christiane Woopen,[1,3] Saskia Jünger[1,4]

[1]1Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health (CERES), University of Cologne and University Hospital of Cologne, Cologne; [2]Center for Hereditary Breast and Ovarian Cancer, University Hospital Cologne, Cologne; [3]Research Unit Ethics, Institute for the History of Medicine and Medical Ethics, Faculty of Medicine, University of Cologne and University Hospital of Cologne, Cologne; [4]Department of Community Health, University of Applied Health Sciences Bochum, Bochum, Germany

ABSTRACT

Personalised methods of predicting breast and ovarian cancer risk through genetic testing increasingly demand a person's understanding and critical appraisal of risk-related information, as well as decision-making and acting upon disclosure of a positive test result. The current study aims at understanding health literacy (HL) among persons at risk of developing familial breast-ovarian cancer (FBOC) from a bottom-up perspective—incorporating their viewpoints into the research process. Its qualitative design integrates an ethnographic-narrative approach and findings from 10 narrative interviews with women who have undergone genetic testing, analysed by using reflexive grounded theory. The collected data reveal the entanglement of the women's perceptions concerning the risk of getting ill, their identity, and their strategies of managing health. The analysis of this interplay provides an empirical basis for approaching HL in its communicative dimension, considering individuals' understandings of health and illness, and emphasizing the role of critical HL.

Introduction and aim of the study

Breast and ovarian cancer belong to the most common types of cancer among women worldwide. Five to ten percent of all breast and ovarian cancer patients develop the disease due to genetic predisposition. In 30 out of 100 cases of patients with breast or ovarian cancer in Germany, a familial accumulation or an early onset of the disease can be observed.[1] Predictive genetic testing became a widespread instrument of determining individuals' hereditary susceptibility for familial breast-ovarian cancer (FBOC), and the increasing research in this field allows for more differentiated and individualised knowledge of various genetic and non-genetic risk factors.[2]

Correspondence: Mariya Lorke, Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health (CERES), University of Cologne, Albertus-Magnus-Platz, 50931 Cologne, Germany.
Tel.: +49.0221.470.89126; Fax: +49 (0)221 470-89101.
E-Mail: mariya.lorke@uni-koeln.de

Key words: Health literacy; risk; narrative interviews; reflexive grounded theoryy.

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Contributions: ML made a substantial contribution to the conception and design of the study, the analysis and the interpretation of data for the work, and the theoretical embedding of the findings; the author also drafted the article. LH made a substantial contribution to the conception, design, and conduct of the study, and revised the work critically for important intellectual content. KR made a substantial contribution to the conception and design of the work and the recruiting process; the author also revised the work critically for important medical and intellectual content. CW made a substantial contribution to the conception and design of the work and revised the work critically for important intellectual content. SJ made a substantial contribution to the conception, design, and conduct of the study, supervised the research process, and revised the work critically for important intellectual content. All authors gave approval on the final version of the manuscript and agree to be accountable for all aspects of the work.

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Ethics approval and consent to participate: Ethics approval was obtained in March 2018, (registration number 18-014) by the ethics committee of the Medical Faculty of the University of Cologne. The study is conformed with the Helsinki Declaration of 1964, as revised in 2013, concerning human and animal rights. All patients participating in this study signed a written informed consent form for participating in this study.

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The German Consortium of Familial Breast and Ovarian Cancer (GC-HBOC), for example, established a multi-gene panel (TruRisk®) for the analysis of risk genes, which currently comprises the core genes *ATM*, *BARD 1*, *BRCA1, BRCA2, CDH1, CHEK2, BRIP1, PALB2, RAD51C, RAD51D* and *TP53*, as well as other genes still being object of current research that needs further validation.

Apart from specific biographical reasons and motivations that may be crucial for each individual case, most women decide to undergo a genetic test after having developed breast or ovarian cancer due to familial predisposition (based on individual assessment or gynaecologist recommendation) or positive test results of relatives. The increasing opportunities of risk prediction confront individuals with the challenge to find and understand relevant information and to critically appraise it, in order to make a decision concerning genetic testing and preventive interventions. We know a lot about the psychological effects of genetic testing on individuals' identity[A] and everyday life,[4,5] the experiences of affected individuals and their families,[6,7] individuals' risk perceptions[B] in the process of decision-making in terms of prevention,[11] and the issue of genetic responsibility.[12] But what do we know about health literacy (HL) among persons at risk of developing FBOC, and what impact does the perception of risk have on individuals' understanding of health and illness and/or vice versa?

Most generally speaking, HL refers to knowledge and skills related to one's health; depending on the respective definition or perspective, this can imply different cognitive, interpersonal, and social skills, and entail a more functional connotation (in terms of basic reading, writing, and literacy skills), a communicative level, and a critical dimension (in terms of appraisal of information or even a social and political engagement concerning health-related issues).[13–15] The number of publications under the heading of HL has risen rapidly in recent years, and efforts continue to define the concept, to expand existing definitions, or to examine them in new contexts.[16] In the phase of conceptualising this study, we employed a working definition of HL based on the existing literature and the integrated model of HL, defining it as a person's set of certain abilities, attitudes and lifestyle, enabling her or him to manage a certain health situation in order to achieve a positive health outcome.[10]

A great number of studies deal with the measurement and quantification of HL as a multidimensional concept. The majority of them primarily refer to functional HL using standardised measurement tools and mixed measurement (self-reporting components and direct testing of certain abilities).[17,18] A few very fruitful qualitative studies deserve closer attention[19–21] that analyse HL beyond its functional dimension, using data from interviews and thereby emphasizing the perspective of those being studied. However, qualitative research on HL to date is still scarce, particularly in the specific clinical field of risk of FBOC.[22,23] At this point in time, we still know very little about people's own perceptions of HL in the context of FBOC and of factors relevant for the management of health-related information and behaviour. An insight into the process of decision-making, attitude towards risk, and the individual coping strategies before, during and after the genetic testing can provide a productive ground for a better understanding of HL in the context of risk.

The current study aims at generating new hypotheses in the research field of HL and risk based on findings from a bottom-up research approach. The leading questions in this article are: i) Which factors account for HL among persons at risk of developing FBOC? ii) How can the empirical findings contribute to the theoretical foundation and conceptualisation of HL?

Methods and research ethics

This study is part of a broader research project on HL (Health Literacy of Persons at Risk – From Information to Action – RisKomp) in persons at risk in four different clinical fields (FBOC, coronary heart disease, psychosis, and Alzheimer's dementia) and uses a qualitative design integrating an ethnographic-narrative approach. This article is based on findings from 10 narrative,[24] open-structured interviews with women who have undergone genetic testing for FBOC. Ethics approval was obtained in March 2018, (registration number 18-014) by the ethics committee of the Medical Faculty of the University of Cologne.

Procedure and participants

The interviewees were recruited at the Centre for FBOC at the University Hospital of Cologne (Germany)

[A] We define identity here as *social identity*,[3] illuminating the human world as selfhood which depends on both an individual's physical body and his/her social world. According to Jenkins, identity is not only about individual values and understandings, but also about interactions through which status, social position, roles and expectations become visible. Furthermore, Jenkins refers to identity as a process rather than a static constant..

[B] In line with the work of other authors,[8–10] risk in the context of our study is experienced and handled in an area of tension between objective and subjective.[9] From a medical/statistical perspective, risk is the probability for a certain person to develop FBOC, based on the outcomes of genetic testing. From a socio-anthropological point of view, risk can be considered as a relational phenomenon that is situated in specific social and cultural contexts. As a way to unravel these "juxtapositions and amalgamations" of perspectives, Boholm proposes considering risk "as a cognitive frame that produces contexts which link an object of risk (a source of potential harm), an object at risk (a potential target of harm) and an evaluation (implicit or explicit) of human consequences;" situated in specific social contexts risk can be thought of as a relational order through which connections between people, 'things' and 'outcomes' are constituted."[9] This understanding of risk also encompasses the varying perspectives of different actors on the same external phenomena;[10] and it is within this cognitive frame that persons confronted with the statistical probability of getting FBOC are required to make their evaluations and to negotiate their individual risk perceptions.

in cooperation with a team of experts in the field of FBOC and genetic testing according to the criteria shown in Table 1. The team of physicians closely involved in the clinical everyday practice and procedures started screening patients' data for eligibility and obtained the patients' agreement to be contacted by the research team. Only individuals who underwent genetic testing were contacted; those who did not, were not included in this study. The researchers arranged the meetings and conducted the interviews. All participants were provided with detailed information on the aims of the study and the research procedure and signed an informed consent for participation. In a time period of five months, all 10 interviews were conducted and preliminarily analysed; in the next six months, all interviews were transcribed and went through an in-depth analysis process.

Narrative interview

The interviews started with an opening question avoiding a direct reference to feeling about risk and rather focusing on the concrete situation in which the first confrontation with the notion of genetic risk happened. Further in-depth questions were pre-formulated based on existing empirical research and were used only if the topic was raised by the interviewee. An additional tool was developed to ensure a constant process of researchers' self-reflection, researcher triangulation, and making researcher's subjectivity visible. The average length of the interviews was approximately one hour. All interviews were conducted in German. For the purpose of this article, the quotations from the interviews used in the analysis part were translated from German into English by the involved researchers including the one who conducted the interview. The different versions of the translation were compared, discussed, and in case of disagreement, a fourth person (also a member of the team but not involved in the research process) was asked for her/his opinion. Socio-demographic data were collected by means of a questionnaire before starting the interview.

Analysis strategy

The process of data analysis was embedded in the reflexive grounded theory,[25] a variation of the grounded theory methodology emphasizing the interaction between the researcher and the research topic/partners/or field as an integral part of the process of knowledge production and considering reflection on this interaction as a source of insight. It combines the grounded theory approach with reflexivity concerning the situatedness of the researchers, the research design, as well as the research process and practices. Reflexive Grounded Theory therefore allows for the integration of the researchers' subjectivity, personal dispositions, or standpoints into the analysis, as well as for the reflection on power relations in the research context.

The data analysis in the current article is based on two data pools – the interviews and the researchers' self-reflection—with the aim of ensuring a comprehensive analytical process encompassing reflexivity, theoretical sensitivity, and triangulation of data and researchers. All researchers and participants in this study were female. The researchers' own understanding of risk grounds in their different academic backgrounds (psychology, health sciences and social anthropology) and in their personal experiences with risk and disease. The three researchers had also been confronted with the risk of getting FBOC to different extents in different phases of their lives and made different decisions on prediction and prevention. These experiences and attitudes have undoubtedly impacted the research process; in line with the principles of the reflexive grounded theory, they were actively addressed throughout all stages of data collection and analysis.

In the first stage of the empirical research, data were analysed parallel to the process of conducting the interviews. Our team arranged researcher meetings on a regular basis and created opportunities to discuss and compare the first impressions and categories that resulted from the first steps of individual open coding. Inductive thematic saturation was reached at the sixth interview.[26] In the second stage of the analytical process, the memos were systematically analysed, and the findings were incorporated into the process of axial coding. In the third stage of the analysis, the two data sources were integrated into a process of selective coding and theory generation.

Participant characteristics

The analysis includes responses of ten women: two women aged between 18 and 30 (Julia, incapacitated for work and Kathrin, working part-time in the health area); four women aged between 31 and 40 (Christina, working part-time in the social area, Jennifer, working fulltime in

Table 1. Inclusion and exclusion criteria.

Inclusion	Exclusion
Participation in genetic counselling taken place	Persons younger than 18 years of age
Group 1: Carrier of a *BRCA1* or *BRCA2* mutation	Mild cognitive impairment or dementia
Group 2: Carrier of a mutation in a moderate risk gene (*e.g. CHEK2*)	Current clinically relevant depressive episodes, anxiety symptoms or suicidal tendencies
Group 3: No mutation detected in one of the known risk genes, but increased statistical risk of disease due to own and/or family anamnesis	
Written declaration of consent of the patient	
German language proficiency that allows for participation in an interview/survey	

the health area, Stefanie, working part-time in the field of economics, and Nadine, working in the health area); three women aged between 41 and 50 (Katharina, working full-time in the social area, Sarah, working fulltime in the IT area and Anna, working full-time), and one woman aged between 51 and 60 (Sabrina, working part-time in the health area). Six of the participants were married, three unmarried, and one divorced. Most participants lived with their families or partners, apart from one who lived alone. Seven participants had a German background and three, a non-German cultural background. All participants had secondary to post-secondary educational background. Four participants suffered from a chronic disease, e.g. thyroid gland diseases. All names used in text are pseudonyms.

Category system and main findings

The main themes and issues that arose in the course of this study can be situated in the context of understanding risk, identity (being a person at risk of developing FBOC), and managing health. These spheres also build the central categories of analysis, contributing to a better understanding of HL in persons at risk of developing FBOC.

Understanding the genetic risk of getting ill - as a feeling, a multifaceted concept, and an individual/relational responsibility

The process of understanding health risk in its different dimensions includes the individual's feeling about risk, its familial dimension, and possible strategies to manage and control the process of risk understanding. This negotiation also entails questions about the credibility of risk when related to everyday life experiences.

Risk as a feeling: between reason and emotions

The results of this study indicate a tension between different interpretational frameworks concerning one's genetic risk: a logical framework, analysing risk based on statistics and medical facts; and an intuitive one, viewing risk on a more affective level through one's own experiences.[8]

With respect to the appraisal of a genetic risk of FBOC, this complex interplay between both frameworks is mirrored in our interviewees' accounts.[8] On the one hand, the demand for genetic testing as a means to objectify risk and as a basis for further decision-making on prevention suggests that in medical settings, *reason* (representing the analytical system) is the dominant mindset among both professionals and patients. On the other hand, our interviewees' narratives demonstrate the importance of *emotions* (representing the experiential system) in the process of interpreting and evaluating risk on an individual level. The decision for genetic testing was described with an emphasis on the role of one's own risk-intuition, and at the same time as a possibility to technicise risk and thereby attain a sense of safety. Sabrina responded to the question of how she was confronted with the risk of getting FBOC for first time saying:

> I somehow knew that I have a high risk, and then I complained to my gynaecologist, and I said to her: I think that I'm quite at high risk, I want to do the test, and then I also wish to act accordingly. And then they said: You do not need to do the test, your cousin is not affected, the youngest and most severely affected family member. We have examined her tissue, and there is no gene. (*PALP2*, breast cancer)

The interviewed women reflect on their endeavour of relating the medical information about the statistical risk probability to their personal feelings towards the risk (in terms of a premonition or an intuitive interpretation of the statistics they have been provided with). When being asked how she values the communicated risk percentages, Jennifer explains this as follows:

> I myself for example, from a purely medical point of view, I understand that they say that you only consider it a medium risk if it is increased up to 40 percent. But for me personally, it felt like close to 50 percent and the chance is actually fifty-fifty whether you will get it or not. (*CHEK2*, breast cancer)

This quotation illustrates the process of relating medical information to one's own feelings. Our interviewees' reflections suggest that the two sources of information (numbers and feelings) are not merely considered a problem of contradiction, but also as a resource for decision-making. This shows that understanding the quantity of risk correctly in mathematical terms and feeling about its quality may be seen as complementary rather than contradictory.

Risk as a multifaceted concept

The depiction of risk in an area between the emotional and the rational is also related to one further perspective of understanding risk and decision-making, namely experiencing risk in manifold facets. These were described with respect to i) illness-logic, i.e. the observation that whether or not someone will be struck by a disease is not always logical in terms of risk factors; ii) inevitability, i.e. the awareness that one cannot influence the fact of having or not having inherited the gene; and iii) a call to action, i.e. the responsibility that one may be able to influence whether or not the gene will eventually result in developing the disease. All our interviewees provided many examples for the paradox of risk in terms of the illness-logic in order to substantiate their decision to listen to their individual feeling. For example, Julia refers to this paradox while responding to the question of how she became aware of the risk saying:

> Well, I knew it before. That sounds stupid, but my grandfather died of cancer, but he was the healthiest man ever—he never smoked and stuff, or drank. (*BRCA2*, breast cancer)

The interviewed women also discuss the pathogenesis of FBOC emphasizing its paradoxical nature between determinism and modifiability: Sabrina sees it as a *genetic bug* and one's own genes as an uncontrollable danger, and Julia as variable, modifiable by stress and way of life:

> Well, you feel as if you were carrying a time bomb with you. (Sabrina, *PALP2*, breast cancer)
> But I just think, somehow, considering how fast-moving society is, and the pressure you feel in working life and so on, people just get sick…. (Julia, *BRCA2*, breast cancer)

Individual and relational responsibility

The feeling of risk in the context of FBOC is a topic which also implies a further relational/familial dimension. The possibility for genetic testing is seen as emanation of the individual's autonomy, on the one hand, and on the other hand, it raises the topic of the distressing effect on the tested person and her/his family and relatives if the result is positive. Asked about her experience with genetic testing, Sabrina said:

> And there is a constant back and forth, right? That you say: I do not want to know it, it is driving me crazy. You almost feel like it's a self-fulfilling prophecy. (*PALP2*, breast cancer)

In this quotation, the notion of responsibility and self-fulfilling prophecy also becomes visible. Women reason on the relation between being *overconcerned* with risk and the illness outbreak, wondering if they themselves could somehow influence its emergence. Responsibility is not only a question concerned with the individual and her impact on the disease emergence, but also with her as a part of the familial system. Christina provides an example for this familial dimension when asked about how her family deals with the results from genetic testing:

> My mother even apologised to me for transmitting the gene to me. But that is not at all her fault. (*BRCA2*, no cancer)

In this case, the genetic risk goes beyond the individual responsibility (in terms of behaving in a way to minimise it) and reveals a further collective dimension. Christina's genetic risk is immediately intertwined with her mother's risk and raises the question of fault, responsibility, and the distribution of blame.

Strategies to manage risk

The different biographic backgrounds influence the strategies the interviewees employ in order to manage the thought about possible sickness in the future or acute onset of a disease in the present. Factors that influence the perception of illness are: i) vicarious experience as in the case of Sabrina, ii) the perception of illness as a normal and universal part of human life as described by Julia, and iii) medically related work experience in the case of Jennifer:

> So, and this horror scenario was something I had then, in the same way, like the images of my mother who died so terribly and then I thought: I have to do it in an extreme fashion [the prevention]. (Sabrina, *PALP2*, breast cancer)
> And if you look into families, there is hardly any family, I would say, without any diseases, or strokes of fate [...] I see diseases as everyday risk." (Julia, *BRCA 2*, breast cancer)
> So… and we've had such a chief physician whom I have to think about all the time. I am actually working in surgery. And he always used to say, he always was in favour of resecting generously. (Jennifer, *CHEK2*, breast cancer)

To sum up, the concept of risk as a feeling in the area of tension between emotions and reason is seen as an important aspect in the processes of perceiving risk and decision-making. Describing risk as a multifaceted concept giving examples based on personal, everyday experience performs an argumentative function in explaining one's own attitude and serves as evidence that medicine/statistics/science are not universal. The question of responsibility is seen in both an individual (doing something that could trigger the disease) and a social (genetic responsibility) dimension.

Identity between quality of life, social environment, everyday life, and stress

This category illustrates the role of personality in the process of dealing with risk and, at the same time, the impact of risk on one's identity[3] and life-world.[27] Women describe their quality of life in a close relation to their personality, social environment, everyday life, and their individual ability to regulate and control stress.

Quality of life

In terms of quality of life, it became clear that the personality determines the individual, subjective definition of the concept. Katharina responds to the question of how she manages her risk saying:

> Well, I'm not in the mood for side-effects [of the preventive medication], if that's what's affecting

> the quality of life. I want to live as well as I can. I want to do sports, make music, work [...]. (*ATM*, breast cancer)

When asked about their understanding of health, Anna and Jennifer responded referring to the term "quality of life." On the one hand quality of life is seen as condition that should be actively maintained in *doing something spontaneously* and actively enjoying life as in the case of Jennifer; on the other hand, it is defined by keeping up with *normal life* and feeling able to live in the *normal* way as explained by Anna:

> I need to take better care of myself and that I also just do such spontaneous things just more often, you know? That I just say: Nope. I have the weekend off and my husband is on duty, so I'm just going to Holland to the seaside, just like that, you know? (Jennifer, *CHEK2*, breast cancer)
> That is, being healthy for me means being able to lead a normal life. That includes work, it includes friendship, it includes family, it includes my partner, it includes sports. Being able to join cultural things, you know? So that I can do all of this. I can lead a completely normal life. And for me in a way that just means being healthy. (Anna, *CHEK2*, breast cancer)

In Anna's words, *normality* relates to the life before knowing about the risk or having cancer, and *quality of life* means to maintain this condition, not allowing risk and illness to take up too much space and thereby endangering the *normal life*. In the case of Jennifer, the risk and the illness can be seen as a ground for actively increasing the subjective quality of life through enriching the *normal life* by spontaneous actions and experiences.

Social environment and everyday life

The concerns related to the concept of quality of life are connected with the feeling of anticipated loss of everyday-life normality, especially in the context of life planning and decision-making with respect to one's own self or in the impact on relatives and family members, as in the case of Jennifer. Asked how knowing about the risk change her life, she responded saying:

> So, I thought: It will never be the way it was, and you will never get back your normal life. And I found that really bad. And so just to have back this normality. And yes, the normality is another one now, but also good. (*CHEK2*, breast cancer)

The knowledge about the results of the genetic testing is also seen in close correlation to everyday-life normality and social relationships. For example, Katharina reports feeling the predicament of *keeping something* (the information about risk) *for herself*, as a secret towards children, parents, or other family members, and to the impact which this has on their social environment:

> Well, you can't always talk about everything [when the children are there], can you? (*ATM*, breast cancer)

Dealing with stress

Another important factor connected to the preservation of quality of life and normality is the concept of stress. The strategies to balance stress in everyday life build the core of understanding quality of life and the concept of HL, which will be described further below. One strategy of stress regulation is to adapt one's personal attitude towards life circumstances by, for instance, becoming more relaxed. Stefanie responded to the question of how does the knowing about risk impact her everyday life saying:

> Just to slow down a little, to be a little bit more relaxed and, you sometimes get to work on that, but it is difficult to put it into practice. (*BRCA2*, no cancer)

A further strategy to balance stress is related to the interaction with others and training one's own ability to put personal capacities into centre as in the case of Sabrina:

> I am allowing myself more time for things; these stressful things where I used to think "I have to, I have to, I have to"—these are more indifferent to me now." (*PALP2*, breast cancer)

Additionally, Christina, for example, has also identified and employed stress management strategies in everyday life that are connected to certain activities, habits, and behaviour:

> Yeah, somehow not to have so much stress all the time. Exercising every day and paying attention to healthy eating, also for my kids. Then… well. Then you also realise that life is short and that you ought to make the most of it as best as you can. (*BRCA2*, no cancer)

The findings of this study show that the concept of quality of life is primarily seen in its individual and subjective dimension, being used as a synonym for *normal life*. Regulating stress inwards through one's own attitude and outwards in the interactions with the social environment is seen as a key factor for preserving quality of life in the context of genetic testing.

Managing health on the crossroad of information, self-reflection, and expectations towards the system

Information and self-reflection, expectations towards the system, and role expectations and definitions in the doctor-patient relationship emerged as central subcategories with respect to the process of managing health.

Information and self-reflection

When asked about how they inform themselves with respect to risk and FBOC, the interviewed women discussed and reflected on their personal strategies of searching for and finding relevant and trustworthy sources of information. For example, Sarah outlined her motivation of getting information in addition to the regular doctor-patient conversations and Kathrin advocated her need or decision to look up information on the Internet:

> [Regarding the search for information on the Internet] Maybe that wasn't quite right, either. But, well, as I said, I thought the more I know, the more I'm in control, and the better that works. But, as I said, it's just, I think that is just such a way one could deal with it, as it were…. (Kathrin, familial cancer history, no cancer)
> Yeah, that's the way it is, you need to critically question everything. I know there are quite a few scientific publications that are not based on real studies. […] However, when I see the websites run by German clinics, by the university hospitals, I can rely on those, since, well, if even a university hospital spread rubbish, that would just be…. (Sarah, familial cancer history, no cancer)

These quotations demonstrate the women's awareness that the Internet as an information channel needs to be consulted with caution and their effort to justify the way they make use of it. Apart from that, Kathrin and Sarah describe a feeling of being unsure and timid in this information process, accentuating the complicated way information is being written as well as difficulties in finding universally correct medical information.

Expectations towards the system

This subcategory evolved in a close relation to the topic of decision-making for risk prediction. In this context, the interviewed women discuss and evaluate the doctor's recommendation of risk-controlling measures, on the one hand, and emphasize the importance of the feeling of making autonomous decisions, on the other. In retrospect, Kathrin, for example, reflected on whether the outcome of the genetic testing had met her expectations and helped her decision-making:

> Well, and in the end, we are human beings and not statistics […]. I first thought, *Well, okay. Maybe we will manage that in one way or another.* And then, nope, [the testing] has not brought me any certainty on no account. It brought me, so I think, uncertainty, and in retrospect, at some point, I thought, *Let's wait and see, what will be, will be, and before that you cannot do anything anyway.* (Kathrin, familial cancer history, no cancer)

Nadine responded to the question concerning her experiences with doctor-patient communication describing her ideal of the doctor's role as empathic, competent, and able to communicate at eye-level:

> I have the feeling that my actual gynecologist is not an incredibly well-informed doctor in this area, because he has a different specialty. But what helped me most was the counselling center for FBOC in the university hospital. I have the feeling that my questions have been answered. And if I have a question, I will go there again. (*BRCA1*, breast cancer)

Asked the same question, Katharina responded thematising her awareness of the role of self-proclaimed "annoying patient" and describes her strategies of how to avoid being seen as such by her doctors:

> You [as a doctor] have to talk to people. I don't want to be annoying either, but I just want to be taken seriously and get answers, right? (*ATM*, breast cancer)

Women also thematise the power relation in the doctor-patient communication and reveal their strategies to cope with it i) by actively reflecting the power constellation and asking questions (in the case of Katharina) and/or ii) by asking for a recommendation on how to decide, adopting the passive role in the communication process (as in the case of Jennifer):

> And nowadays, it is often still like that, the doctor is way up high and the patient has to, as it were, like obey or so. (Katharina, ATM, breast cancer)
> But you really are, you want to, well, the perspective is really a different one and you just want that *other* people, so, that the doctors decide on your behalf. Well, I could not have made many of the decisions by myself. (Jennifer, *CHEK2*, breast cancer)

The ability to manage health and risk is seen as the competence to find relevant information and adapt it to the individual context in a constant process of self-reflection, critically estimating whether a certain recommendation fits into one's own life-world or not. The concept also includes a systemic dimension manifested in the doctor-patient relationship – being aware of the role-attributions that professionals assign to patients, being able to formulate one's own role-expectations towards professionals, and working out strategies to manage and reflect on this power-constellation.

Discussion and implications for practice

The findings of this study allow for insight into different levels of knowing about, perceiving, and dealing with an increased risk of developing FBOC. The women's narratives show the entanglement of managing one's health, the risk of getting ill, and one's identity, as manifested through the individuals' description of their risk perceptions. In the following, we will first discuss these risk narratives, interpret their meaning in terms of HL, and then relate our empirical data to existing concepts and theories of HL, discussing possible implications for research and practice.

The meaning of health risk in the context of FBOC

Our study revealed the intertwining of meaning-making with respect to one's risk and HL. In our interviewees' narratives, a health risk turns into a risk of getting ill or something that can let the illness break out and develop. This shift in the meaning of risk speaks for an increased awareness of the possibility of getting breast or ovarian cancer and a decreased risk of the possibility to maintain the condition of not having cancer in the present and future. In the case of individuals with no manifest cancer disease, this can also mean a shift in the self-attributed role definition –from a healthy individual to a patient or carrier of hidden genetic thread. As Gunn et al. have demonstrated in their study on women at risk of developing FBOC, it is essential to sharpen health communicators' sensitivity for the risk explanation models of advice seekers.[28] In the following discussion, we will address three conclusions regarding interviewees' risk perceptions and their impact on HL in the sense of a person's management of health information and health behaviour.

Feeling about and understanding of risk as a multifaceted concept

Our findings show that the appraisal of risk has a dualistic nature: intuition is seen as a trustworthy source of risk awareness; at the same time, it gets meaningful only if it attains the status of factual knowledge, providing some extent of scientific value that can be quantified, measured, and observed. The interviewed women see risk as a theory of probabilities and statistical data that should be taken seriously, but at the same time they oppose these objectivity claims to their everyday experiences. These findings can be discussed within the framework of Slovic et al.'s theory of risk, giving us more information about the way individuals realise, perceive, and negotiate risk within their experiential system, questioning the attributed value of its accurate numerical perception.[8] This underlines that risk literacy is much more complex than simply understanding risk in correct statistical terms. Our findings draw a specific picture of risk in the context of prevention, locating genetic risk in closer proximity to disease than to health; genetic predisposition is perceived as a dormant disease that can break out under certain conditions. With a view to the counselling practice, we recommend reserving a definitional space for discussing genetic risk vs. disease (incorporating patients' explanatory models) in the patient-doctor communication and genetic counselling.

Genetic testing as a signpost and as a trigger for individual risk management

According to our findings, intuition is often the reason for choosing genetic testing, and the testing procedure is seen as a way to technicise one's intuition and give the subjective feeling of fear and uncertainty an objective, medically approved face. Dealing with risk consists of renegotiating its dualistic nature in each individual situation of decision-making and in the construction of a person's individual life narrative before and after genetic testing. With respect to healthcare practice, these findings can offer a fruitful ground for future work in the sphere of genetic counselling and communication, delivering focal points for more patient-centred communication by addressing the individual's lived experiences, identity, and life-world.

Risk in a close relation to (hypothetic) disease perceptions

The ideas about the potential disease may be crucial for dealing with and interpreting risk.[22] These often arise based on past experiences of others (often family members, friends, or patients if the person works in healthcare). In addition, the understanding of disease as a phenomenon varies between a universal dimension, being seen as an almost normal condition (all people have some disease), and a personal dimension, considered as a particular threat due to one's own risk genes. This DNA fraught with risk is, on one hand, seen as a trigger or even an early stage of the disease, and, on the other hand, as a matter of a person's own responsibility. As a recommendation for counselling practice, both the perception of the potential illness and the topic of individual responsibility (not only in terms of agency, but also as a possible burden) should, in our opinion, gain more relevance in the patient-doctor-communication.

Health literacy in the context of risk – different faces and diverse facets

The above outlined facets of risk perceptions among individuals who have undergone genetic testing in order to learn more about their risk of getting FBOC open up a new possible perspective of approaching the concept of HL. In the following, we will embed our findings into three conceptual dimensions of HL discussed in the recent literature.

Health literacy between personal and relational concerns

The findings of our study mirror the academic discussion on HL, defining it as an individual set of abilities, attitudes and lifestyle,[16] evolving within a specific health/disease situation,[20] manifested through and formed by communicative practice.[29] We argue that in the context of risk, HL should be understood in both its individual and relational dimension, emphasizing its meaning as communicative action.[30]

As the results of our study show, the way individuals deal with health risks is strongly influenced by their own identity. The personal understanding of quality of life, the role of stress, and the social environment have an impact on how individuals deal with risk and illness. Similar to the findings of Sanders et al.[31] our study shows that being an observer of someone else's suffering leads to the projection of these impressions and fears on one's own possibility to become ill and thus forms the understanding of health-oriented behaviour. This entanglement between the individual and the collective/relational dimension of the concept of HL leads us to ethical issues regarding the fine line between agency and genetic responsibility. Our results are in line with existing studies,[12,32] showing that genetic risk is seen not only in its medical relevance in terms of prediction and prevention among family members, but also as a factor influencing social and family relationships. Referring to this, we strongly support the call by Maddock et al.[33] for improvements in risk communication, emphasizing the need of paying attention to the topic of *telling the family*. In the counselling practice this may imply the use of strategies to increase awareness for the relational responsibility in a familial context, providing recommendations for communicating risk to family members, and encouraging individuals to engage in reflections on the consequences of knowing about risk for themselves and for their family members. On an organisational level, it may be helpful to integrate and further develop complementary family counselling.

Health literacy as interdependence between individual and (health) system

HL is mostly seen as an individual-centred concept which means that individuals apply a set of abilities and attitudes to manage health information in a concrete health/disease situation in order to achieve the best possible health outcome.[16] Nevertheless, a striving for enhancing the organisational/systems-related dimension of the concept can be observed in the academic field.[34] In our study, this dimension becomes visible through the description of the expected roles of doctors in the consultation and healing process.

Holmberg et al. found that the most important factor for deciding on the intake of a certain medicine for the treatment of breast cancer was the doctor's recommendation.[35] On one hand, this can mirror trust in the search for orientation in an ambiguous situation. At the same time, it may also demonstrate the power gap in an existentially threatening decision-making situation. For example, Dixon-Woods et al. have shown, in their research among women who consented to surgery in obstetrics and gynaecology, the weakness of the consent process as a safeguard of autonomy (p. 2742) in the context of hospital structure and rules of conduct.[36] Our findings suggest similar mechanisms in the case of decision-making on risk prediction and preventive interventions—both the impact of doctors' recommendation on a certain preventive decision and the felt power gap in the consulting situation, emerged as relevant categories during the research. Nevertheless, our study does not provide enough data to draw general conclusions about shared decision-making in the context of risk, and, hence, calls for further research on this topic.

According to our findings, the concept of stress appears to play a strategic role in the process of coping with health risk. Our analysis showed that our interviewees address stress both as an alert system enabling a successful risk control and, at the same time, as an external and internal source of hidden and uncontrollable danger. While the internal danger is associated with the feeling of anxiety, the external one is closely related to stress caused by the health system and can be discussed in the wider context of organisational HL. While the health system is seen as a source of healing in terms of risk control, it is also perceived as a source of stress that can provoke a disease breakout. Being health literate, from the perspective of the person at risk, in this context not only means complying with the health system and correctly understanding risk information, but particularly finding an individual balance to regulate both sources of stress. From the perspective of organisational HL, it is worth addressing the question of how a system can reduce stress in the case of genetic prediction and how it can provide a supportive environment for individual HL.

Our study provides some focal points for understanding HL in its communicative dimension;[29] this is in line with the findings of Sarangi et al.[37] who describe risk assessment and management as a dynamic process of negotiation between advice seekers and professionals, thereby co-constructing and putting into perspective the meaning of risk. We strongly believe that for research and counselling practice it will be fruitful to pursuit further research on possible tools and instruments that may support the process of interaction as a space where individual and system meet, and that could contribute to the evolution of a joint, collaborative HL.

Critical health literacy as a resource for risk savvy

The interpretation of the risk narratives in the context of FBOC and their relation to the concept of HL discloses one further crucial dimension of handling health information on risk – *critical* HL as the ability to assess the credibility and applicability of the risk information and to challenge its meaning.[13] The findings of our study suggest that it is closely intertwined with quality of life; in particular, with regard to the critical appraisal of information and the ability to assess its personal relevance.[13] In the context of our research, critical HL becomes relevant in the process of relating health information to one's subjective quality of life. The women's narratives reflect an attempt to carefully select and apply those pieces of information which do not interfere with their quality of life in an inacceptable way and, hence, outweigh the potential health benefit. While the sacrifice for the future and the loss of the feeling of not knowing is seen as a justified sacrifice in the name of life, the sacrifice in the present is seen as burden and a cut in the individual quality of life. The delicate trade-off between benefits and harms, expected gain and taking a loss was also discussed by Bloom et al. with respect to prophylactic mastectomy; they found that women were ready to pay an unexpectedly high price (i.e., sacrificing their breast) for a relatively small reduction of risk.[38] Based on their findings, the authors recommend that instead of putting risk statistics at the centre of communication, physicians should rather emphasize patients' lived experiences in order to support them in being prepared for the emotional and physical consequences of their decision. With respect to the practice and in line with this recommendation, we argue that the promotion of critical HL may enable an individual not only to critically analyse information,[14] but also to incorporate the identity (attributed roles and expectations), life narratives about health and risk, familial relationships, and everyday situations which may be influenced by the knowledge of genetic risk or the distress before testing. This is why we believe that it might be a winning approach to search for ways of promoting critical HL in the counselling practice, embracing the concept of subjective quality of life, and integrating it into institutionalised communicative action.

To sum up: The genetic testing is not an *event* that triggers and forms patients' attitudes towards the questions of risk, health and illness. It is much more a *process* that brings these attitudes, values, and ideas to the surface. This is the reason to suggest that patients' explanatory models of risk, their general attitude towards health and disease, their lived experience[39] and biographical background should be taken into consideration in the course of genetic counselling in order to promote both individuals' and doctors' HL.

Methodological reflection, strengths, and limitations

Limitations on two different levels – setting and methodology – need to be discussed in the context of this study. The definition of inclusion and exclusion criteria was chosen in close agreement with medical experts according to the current state of medical evidence concerning risk prediction in the field of FBOC. In this way, persons who believe to be at risk without having a medical proof of their intuition in terms of genetic testing were excluded from our study. Hence, the composition of our sample does not unrestrictedly mirror the claim "to focus on the subjective perceptions of risk and HL." Apart from that, we also excluded persons who had been recommended to participate in a genetic testing and decided against it. In addition, in the case of FBOC, like for many other conditions, a clear demarcation between *not at risk*, *at risk*, and *ill* is not always possible (e.g., in the case of women who had breast cancer and underwent a genetic testing for the healthy breast). Hence, a differentiated definition of diverse *at-risk* conditions to be eligible for our study was needed. Based on our experience, we therefore recommend considering time for discussion and agreements with the respective clinical partners.

Conclusions

Given the increasing discussions and critical voices concerning the theoretical anchoring and conceptualisation of HL and the large variety of its existing definitions in recent years, the findings of this study suggest some complementary cornerstones for theory generation based on qualitative data, approaching HL from a bottom-up perspective. In our opinion there is a need for more explorative, collaborative, and interdisciplinary research in this field. We, therefore, call for an alternative and more holistic approach to HL in science, medical practice and research, and the development of tools that address both provider and recipient of health services at once.

Risk prediction in the context of health and disease is always a call for action and can have positive, but also negative, consequences for an individual's life. In the case of genetic risk, it is not only a call for action for the affected person, but also for relatives and family members. In this context, the relational, collective dimension of HL is crucial for the better understanding of the concept and needs to be considered when developing HL promoting interventions.

Technical innovations in the field of genetics and predictive medicine will beyond doubt lead to the detection of an increasing number of risk factors. This will present HL research, politics, and public health for the next generations with the challenge of mediating this ever-expanding medical field with corresponding considerations concerning decision-making, prevention, and stress management in the view of persisting statistical uncertainty. We, therefore, believe that a definitional space needs to be reserved for discussing genetic risk vs. disease, incorporating patients' explanatory models in patient-doctor communication and in genetic counselling.

References

1. Rhiem K, Bücker-Nott H-J, Hellmich M, et al. Benchmarking of a checklist for the identification of familial risk for breast and ovarian cancers in a prospective cohort. Breast J 2019;25:455–60.
2. Hauke J, Horvath J, Groß E, et al. Gene panel testing of 5589 BRCA1/2-negative index patients with breast cancer in a routine diagnostic setting: results of the German Consortium for Hereditary Breast and Ovarian Cancer. Cancer Med 2018;7:1349–58.
3. Jenkins R. Social identity. 2nd ed. London: Routledge, 2014.
4. Appleton S, Fry A, Rees G, Rush R, Cull A. Psychosocial effects of living with an increased risk of breast cancer: an exploratory study using telephone focus groups. Psycho-Oncology 2000;9:511–21.
5. Caiata-Zufferey M. Genetically at-risk status and individual agency. A qualitative study on asymptomatic women living with genetic risk of breast/ovarian cancer. Social science & medicine 2015;132:141–8.
6. Bluman LG, Rimer BK, Regan Sterba K, et al. Attitudes, knowledge, risk perceptions and decision-making among women with breast and/or ovarian cancer considering testing for BRCA1 and BRCA2 and their spouses. Psycho-Oncology 2003;12:410–27.
7. Kenen R, Arden-Jones A, Eeles R. Healthy women from suspected hereditary breast and ovarian cancer families: the significant others in their lives. Eur J Cancer Care (Engl) 2004;13:169–79.
8. Slovic P, Finucane ML, Peters E, MacGregor DG. Risk as analysis and risk as feelings: some thoughts about affect, reason, risk, and rationality. Risk Anal 2004;24: 311–22.
9. Boholm Å. The cultural nature of risk: can there be an anthropology of uncertainty? Ethnos 2003;68:159–78.
10. Boholm Å, Corvellec H. A relational theory of risk. J Risk Res 2011;14:175–90.
11. Klitzman R, Chung W. The process of deciding about prophylactic surgery for breast and ovarian cancer: patient questions, uncertainties, and communication. Am J Med Genet 2010;152A:52–66.
12. Etchegary H, Miller F, deLaat S, Wilson B, Carroll J, Cappelli M. Decision-making about inherited cancer risk: exploring dimensions of genetic responsibility. J Genet Couns 2009;18:252–64.
13. Chinn D. Critical health literacy: a review and critical analysis. Soc Sci Med 2011;73:60–7.
14. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promot Int 2000;15:259–67.
15. Liu C, Wang D, Liu C, et al. What is the meaning of health literacy? A systematic review and qualitative synthesis. Fam Med Community Health 2020;8:e000351.
16. Sørensen K, van den Broucke S, Fullam J, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health 2012;12:80.
17. Altin SV, Finke I, Kautz-Freimuth S, Stock S. The evolution of health literacy assessment tools: a systematic review. BMC Public Health 2014;14:1207.
18. Haun JN, Valerio MA, McCormack LA, Sørensen K, Paasche-Orlow MK. Health literacy measurement: an inventory and descriptive summary of 51 instruments. J Health Commun 2014;19:302–33.
19. McKenna VB, Sixsmith J, Barry MM. A qualitative study of the development of health literacy capacities of participants attending a community-based cardiovascular health programme. IJERPH 2018;15.
20. Samerski S. Health literacy as a social practice: Social and empirical dimensions of knowledge on health and healthcare. Social Sci Med 2019;226:1–8.
21. Jordan JE, Buchbinder R, Osborne RH. Conceptualising health literacy from the patient perspective. Patient Educ Couns 2010;79:36–42.
22. Rutherford EJ, Kelly J, Lehane EA, et al. Health literacy and the perception of risk in a breast cancer family history clinic. Surgeon 2018;16:82–8.
23. Ektir B, Yilmaz M. Breast cancer-related knowledge levels and health literacy in working women. Int J Caring Sci 2017;10:1658–68.
24. Nohl A-M. Interview und Dokumentarische Methode. Wiesbaden: Springer, 2017.
25. Breuer F, Muckel P, Dieris B, eds. Reflexive grounded theory, Eine Einführung für die Forschungspraxis. 4th ed. Wiesbaden: Springer, 2019.
26. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant 2018;52:1893–907.
27. Schutz A, Luckmann T. Structures of the life world. Lodon: Heinemann, 1974.
28. Gunn CM, Bokhour B, Parker VA, et al. Exploring explanatory models of risk in breast cancer risk counseling discussions: NSABP/NRG Oncology Decision-Making Project 1. Cancer Nurs 2019;42:3–11.
29. Harzheim L, Lorke M, Woopen C, Jünger S. Health literacy as communicative action—A qualitative study among persons at risk in the context of predictive and preventive medicine. IJERPH 2020;17:1718.
30. Habermas J. Theorie des kommunikativen Handelns. 1st ed. Suhrkamp, 1981.
31. Sanders T, Campbell R, Donovan J, Sharp D. Narrative accounts of hereditary risk: knowledge about family history, lay theories of disease, and "internal" and "external" causation. Qual Health Res 2007;17:510–20.
32. Hallowell N. Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information. J Med Ethics 2003;29:74–9.
33. Maddock C, Camporesi S, Lewis I, Ahmad K, Sullivan R. Online information as a decision making aid for cancer patients: recommendations from the Eurocancercoms project. Eur J Cancer 2012;48:1055–9.
34. Farmanova E, Bonneville L, Bouchard L. Organizational health literacy: review of theories, frameworks, guides, and implementation issues. Inquiry 2018;55.
35. Holmberg C, Bandos H, Fagerlin A, et al. NRG Oncology/National Surgical Adjuvant Breast and Bowel Project Decision-Making Project-1 Results: decision making in breast cancer risk reduction. Cancer Prev Res (Phila) 2017;10:625–34.
36. Dixon-Woods M, Williams SJ, Jackson CJ, Akkad A, Kenyon S, Habiba M. Why do women consent to surgery, even when they do not want to? An interactionist and Bourdieusian analysis. Soc Sci Med 2006;62:2742–53.
37. Sarangi S, Bennert K, Howell L, Clarke A. 'Relatively

speaking': relativisation of genetic risk in counselling for predictive testing. Health Risk Society 2003;5:155–70.

38. Bloom DL, Chapman BM, Wheeler SB, et al. Reframing the conversation about contralateral prophylactic mastectomy: Preparing women for postsurgical realities. Psycho-Oncology 2019;28:394–400.

39. Holmberg C, Waters EA, Whitehouse K, Daly M, McCaskill-Stevens W. My lived Experiences are more important than your probabilities: the role of individualized risk estimates for decision making about participation in the Study of Tamoxifen and Raloxifene (STAR). Med Decis Making 2015;35:1010–22.

3. DISCUSSION

The discussion of the contributions included in the current cumulative thesis will comprise two main parts: one theoretical, the other practice-oriented. In the first part, the findings from all three articles will be merged and related to each other. The results of this analysis will be condensed into five insights for future research on health literacy and risk in predictive and preventive medicine. Furthermore, these theoretical aspects will be contextualised within medical and counselling practice. In the second part of the discussion, these findings will be operationalised and translated into a module-box for trainers, coaches and instructors which can be used for the conceptualisation and development of teaching units or courses on health literacy, communication and risk.

3.1 INSIGHTS FOR PRACTICE AND FUTURE RESEARCH

During the analysis of the merged findings from the three articles, five thematic strands emerged that need to be considered when applying a culture-sensitive approach to risk and health literacy in the context of predictive and preventive medicine. In short: Gaining more understanding for individuals' explanatory models of risk and health in the context of their lifeworlds adds additional layers of understanding risk in medicine that need to be reflected upon; approaching the risk consultation as an intercultural encounter may increase awareness for the different cultural embeddings of risk and the narratives which define them, and may improve communication skills. Furthermore, sharpening sensitivity for the various cultural embeddings of risk in health increases critical health literacy and contributes to a broader critical approach in terms of the distribution of power and blame. With respect to future research on health literacy and risk addressing culture in narrower sense (in terms of nationality, ethnicity, or migration background) this thesis also invites a re-negotiation of the concepts of vulnerability and offers practice-oriented recommendations for approaching the concepts in diversity-sensitive contexts.

3.1.1 HEALTH LITERACY AS ENCOUNTER - EMPOWERMENT TROUGH INTERACTION

The findings of the included articles suggest health literacy and risk can be approached as a communicative action. Embedded within the theory of Habermas (Lorke et al. 2020), this means that the concept of health literacy can be seen as a co-production of meanings and understandings of risk in the context of the medical consultation, everyday-life experiences and health encounters. The communicative dimension of the concept, when understood in the Habermasian sense, should mirror a true understanding between the engaged parties and a process of information exchange which is reciprocal and non-hierarchical (Habermas 1981), or

– as described through the perspective of the *persons at risk* – “communicating at eye level” (Lorke et al. 2021a). In the context of health literacy and risk, this implies not only an accurate understanding of the communicated numbers and medical data, but also an awareness of the culture in which this knowledge is being produced, embedded and communicated. Health literacy can be thus seen as a “communicative action that enables professionals, patients, and their relatives to use the risk consultation for negotiating the lifeworld and system narratives, and achieve a social and systemic integration of the condition of ‘being at risk’” (Lorke et al. 2020).

Nevertheless, studies on health literacy or/and risk show that for many individuals the recommendations of health professionals are essential (Rowlands et al. 2017) in the process of decision-making. This illustrates the uniqueness of medical counselling and highlights the features of the real-life communicative action in which communication is both hierarchical and non-reciprocal. In Habermasian words, such communication lead by the doctor’s recommendation can be understood also as a form of strategic communication (Lorke et al. 2020). In predictive and preventive medical practice, where decisions on risk are primarily based on complex medical and statistical knowledge and understanding (Sarangi et al. 2003), strategic communication can hardly be avoided due to discrepancies in the levels of knowledge and experience and the limitations due to the health system (e.g. lack of time for the counselling practice). In light of these circumstances, rather than strictly attempting to avoid strategic communication, it may be more appropriate for both parties to become aware of the fact that it is not uncommon in the process of risk communication. The consultation encounter can be seen as the space within which health literacy and risk understanding are being constructed and negotiated. Patients and doctors should be encouraged to engage in communicative action and increase awareness for the role of strategic communication (Lorke et al. 2020).

Advice-seekers and professionals meet and negotiate risk and health in the process of communication, and communication can never be detached from culture. As Scrimshaw (2019) describes in a recent publication, “people hear science communication through a series of filters such as generation, culture, language, literacy and socioeconomic status” (p. 7650). These filters bring us closer to a culture-sensitive approach on health literacy and risk. An alternative bottom-up perspective is needed in order to learn more about the way individuals define and understand health literacy. This perspective should reflect on health literacy’s cultural embedding to illuminate blind spots and definitional spaces. The included articles show that *persons at risk* understand, explain, feel and decide on risk, based on factors and attitudes (individual lifeworld) that are not considered to be part of rational decision-making in the field of evidence-based medicine (medical culture) (Lorke et al. 2021a; Lorke et al. 2021b). Risk-communication between professionals and patients can be thus defined as an intercultural encounter (Kleinman 1978; Napier et al. 2014) which includes different risk and health understandings, role-expectations and strategies to handle the feeling of uncertainty and trust.

Looking at health literacy, risk and communication through the prism of an intercultural encounter may be highly beneficial with regard to the promotion of health literacy. The lessons learnt from the field of inter- and transcultural communication and competence in the last few decades may be adapted to the field of health literacy and risk (several suggestions in the sphere of education and training are included in the module-box in chapter 3.2). The findings of the included articles show three ways of promoting health literacy which encompass culture: (1) targeting the counselling encounter and not solely the needs of a certain demographic group; an insight from long-term attempts to develop tailored solutions to enable intercultural communication (e.g. through culture-specific trainings based solely on nationality) is that such approaches are neither beneficial nor practical in everyday health related communication (Shepherd 2019); (2) employing participatory approaches in the development of instruments of health literacy promotion: Engaging individuals as judges of health information may both increase the self-determination of members of marginalised communities (Morales 2017) and promote health literacy; (3) targeting the promotion of organisational health literacy and intercultural opening at once: Since both concepts address people's diverse information needs and aim to reduce/remove access barriers to health care, they need to be applied simultaneously. Neither nationality nor ethnicity justify a target-group approach.

3.1.2 THE POWER OF RISK-NARRATIVES - PROMOTING HEALTH LITERACY OF INDIVIDUALS AND ORGANISATIONS

The three included articles show that how risk is narrated in everyday life, in medical practice, or while doing research is crucial both for the ways risk is perceived and lived by the so-called *persons at risk,* and for the better understanding of how risk is contextualised and classified in a specific environment. Narratives on risk also impact the blurring of the line between risk and disease in the decision-making process (Aronowitz 2009). While in the context of mental health, individuals perceive risk as a kind of warning system (outside the body) which may support the balancing of threat and confidence (Lorke et al. 2021b), in the field of genetics, risk is seen as a dormant disease (hidden inside the body) which – if triggered – may anytime break out (Lorke et al. 2021a). These different perceptions of risk may be explained on the one hand by the different contexts in which risk is determined, and on the other hand by the possible preventive measures and decision-making upon disclosure of a positive test result. Nevertheless, in both cases risk is a concept which is based on statistical probabilities. Therefore, a sharpening of the border between risk and disease is essential (Lorke et al. 2021a), especially in the case of genetic risks.

Persons who face health risks "construct their personal narratives in order to find a meaningful way to manage their situation and to (re-)gain a sense of agency, embedded in their biographical and social context." (Lorke et al. 2021b). A closer look at these narratives may provide insights into people's risk perceptions and lifeworlds, and reveal possible competing values between the individual and the system. In the context of medical counselling, a person's individual health literacy is faced not only with the challenge of accurately appraising the communicated statistical risk prognosis, but also with managing "the emotional confrontation with the new, identity-relevant role of being 'a person at risk'." (Lorke et al. 2020).

The sensitive use of language in terms of risk is one possibility to bridge diverging values between system and individual. Svendsen (2006) found that there is a gap between the social production of knowledge on risk and kinship in the institutional setting of counselling, and the social experience of risk and kinship in daily life. For a culture and health literate organisation, it is essential to address this gap through both increasing awareness and translating medical risk knowledge into everyday language. This goes beyond the idea of translating medical terms and concepts into *plain* language. The conscious use of language should rather support the process of acquiring and understanding knowledge for health, and the ability to evaluate this knowledge in the context of family history, ethnicity and culture (Rowlands et al. 2017). If this translation process gets integrated into professionals' qualifications, this may also enhance their communication abilities and empathy and thus improve humanism (Vargas Pelaez et al. 2018). Training in the translation of statistical probabilities into everyday-relevant meanings grounded in experiences may enable professionals to develop strategies of addressing possible gaps in meaning-making during the risk consultation, instead of solely emphasising the accurate understanding of numbers or medical terms. In the context of organisational health literacy and intercultural opening, the same also applies for the distribution of foreign language material – it is a minimum prerequisite for access to predictive medicine but is not enough to enable patients to engage in communicative action. On that basis, I therefore recommend diversity-oriented risk communication, rather than culture-specific guidelines for consulting patients with different cultural backgrounds.

The findings in the included articles also demonstrate that narratives on risk and health also play a central role beyond the process of decision-making on testing or prevention. Furthermore, these narratives become an essential part of a person's health literacy in the process of negotiation before, during and after a specific diagnostic or preventive decision-making on risk. Promoting the health literacy of individuals and organisations includes the development of interventions that target the different stages of the process of dealing with risk, not only risk understanding during the counselling encounter.

3.1.3 HEALTH LITERACY, SUBJECTIVITY AND CRITICISM OF THE RISK DISCOURSE

Approaching health literacy in the context of risk in a culture-sensitive manner will be neither coherent nor meaningful if it does not take existing criticism of risk discourse into account and relate it to the findings of the included articles. Heibges (2019) provides a brief summary of this criticism in the field of health from a socio- and medical anthropological point of view, outlining the following three major themes: (1) a lack of a clear border between diagnosis and risk, which may lead to the construction of identities (of *healthy* individuals) which are based on (still) non-existent disease; (2) the medical statistical information on risk does not offer concrete indications for individuals' life prognosis and lifeworld; these mismatching medical and individual agendas may lead to more insecurity and the feeling of threat instead of increasing confidence in decision-making; (3) a trend for individualised responsibility in predictive and preventive medicine as a form of power and control (or bio-politics, speaking in Foucault's terms (Foucault 2019)). The results of the included articles provide several indications for the importance of reflecting on all these critical topics when discussing health literacy.

The communication of a certain health risk may lead to a blurred understanding of health, risk and disease (Lorke et al. 2021a; Lorke et al. 2021b). Since individuals interpret risk information in the framework of their individual experiences, values and emotions, a certain risk prediction may affect the process of identity construction. The emergence of identity based on a statistical probability or a non-existent disease not only impacts the one segment in life related to health prevention, but can also infiltrate all spheres of individual's lifeworld and visions of the future. In both cases of mental risk (psychosis) and genetic risk (familial breast and ovarian cancer) prediction, individuals evaluate the health information, as already mentioned above, as it is embedded into their individual family history and in the context of their ethnicity and culture (Rowlands et al. 2017). These frameworks also determine the understanding of the risk genesis (Lorke et al. 2020), how health risks are dealt with (Lorke et al. 2020) and the impact of a person's identity in the process of understanding risk (Lorke et al. 2021a). In the context of health literacy promotion, awareness of the importance of identity in the process of prediction and prevention among both advice seekers and their doctors should be increased, and critical health literacy at both the individual and organisational level should be promoted.

The statements above show on the one hand that individuals use their own frameworks to interpret and evaluate communicated information of risk, and on the other hand that power of definition with respect to health risks “predominantly lies with professionals, i.e., scientists or health professionals, implying that there is one appropriate way of understanding and interpreting risk-related information, and transforming it into health promoting behaviour” (Lorke et al. 2021b). In the context of this contradiction, the findings of the included articles illustrate the essential role of subjectivity in the way risk and health are explained, communicated and lived. In order to approach and address the concept of health literacy in the context of risk, subjectivity needs to be reflected on and referred to on a personal, systemic and social level. The qualitative and ethnographic data in this research provide insights into individual worlds, meanings and perceptions, which may question the *objective common sense* on health and risk and disclose blind spots in the operationalisations of health literacy for both theory and practice. This may provide an opportunity to strengthen the preventive function of risk prediction, thereby increasing confidence and agency and reducing stress caused by the feeling of insecurity and threat. According to the findings in this thesis, the process of relating medical information to an individual’s own feelings, emotions and perceptions is described as a resource for decision-making (Lorke et al. 2021a). Instruments that increase awareness for this process and encourage advice seekers to reflect on their emotions and lifeworld while evaluating risk information or during the process of decision-making on prevention, may be also beneficial for promoting health literacy in the context of risk.

According to the data on the lived experiences and everyday knowledge of the persons involved in this study, subjectivity both challenges and empowers the development of coping strategies concerning risk, health and communication. The data show that views on risk and the medical encounter depend on personal cultural background, and are related to certain values which may compete (e.g. different attitudes towards preventive measures or risk communication which result in different expectations of the counselling encounter). An attempt to eliminate this subjectivity may reinforce lived culture-centrism, leading to discriminative behaviour locally, and endangering cultural diversity globally. Furthermore, while culturalisation of risks on an epidemiological level may positively improve professionals’ awareness for ethnical diversity in the context of medical treatments, it may overshadow other factors related to risk such as poverty, discrimination and social exclusion (Ingleby 2012). I therefore support the idea of explicitly addressing subjectivity during risk communication between professionals and patients in order to make possibly competing values visible. Future research on this topic should be encouraged to integrate a participatory perspective in defining the central concepts based on interviewees’ individual perceptions and experiences.

3.1.4 ‘VULNERABILITY’ OF MIGRANTS IN THE CONTEXT OF RISK AND HEALTH LITERACY

Since risk can be thought of as “relational order through which connections between people, ‘things’ and ‘outcomes’ are constituted” (Boholm 2003) and individuals not only *think* but also *feel* risk (Slovic et al. 2004), the concept of vulnerability should be negotiated in the context of risk prediction. The findings generated in the included articles reveal the following dimensions of vulnerability. If individuals are not to be regarded as “sinners or victims” (Mechanic und Tanner 2007), these dimensions need to be taken into account when developing instruments for promoting health literacy in the context of risk:

(1) *Vulnerability in the communicative action*: In order to successfully engage in a communicative action with their doctors, advice seekers need to comprehend the communicated risk prognosis. To achieve this, solid background knowledge and training is essential for both parties engaged in the communication process. Since such prior knowledge is not typical for advice seekers, counselling is a priori coined by *epistemic injustice* (Carel und Kidd 2014). In this context, patients should be encouraged to “understand their own vulnerability based on risk calculations” (Hunt et al. 2006). Furthermore, the risk consultation in the context of predictive and preventive medicine also places “special demands on individual health literacy” (Lorke et al. 2020), especially with respect to critical health literacy and the ability to reflect on “strategic communication” (Lorke et al. 2020).

(2) *Vulnerability in identity and lifeworld:* Increasing awareness of vulnerability in the context of risk and health literacy does not automatically improve shared decision-making and patient-doctor-communication, since the impact of the communicated risk goes beyond the counselling itself. In the context of mental health, labelling individuals with *at risk* status challenges their lifeworlds in two different ways: (a) they are faced with the challenge to achieve a balance between normality (as it was before knowing about the risk) and prevention while avoiding stress; (b) they also need to negotiate the entanglement between symptoms and personality when defining their own identity (Lorke et al. 2021b). In the case of genetic testing, one further dimension of vulnerability emerged – a kind of distributed vulnerability through genetic responsibility and the impact of genetic testing on a person’s family and relatives (Lorke et al. 2021a). Therefore, sharpening the sensitivity for the patients’ risk explanation models (Gunn et al. 2019), the issue of “telling the family” (Maddock et al. 2012), and increasing awareness for strategic communication and epistemic injustice in the counselling process are crucial aspects in developing instruments for health literacy promotion in the context of risk.

Approaching health literacy and risk in a culture-sensitive way in highly diverse societies requires us to pay special attention to ethnicity and migration background. In existing literature, such attention is directed towards the relation between migration background and the health system as well as towards the levels and specifics of individual health literacy among migrants and their families. Recent studies have found that individuals with migration backgrounds have difficulties orienting themselves in the health care system of the host country (Kostareva et al. 2020) and other studies have pointed out multilingualism as a factor which enables comparisons between information in different languages produced in the context of different health systems (Adam und Carol 2020). The recent work of Adam and Carol (2020) reveals the relation between health literacy and migration background, which can in turn be related to the current findings in the context of risk. In this way, it becomes possible to identify overlaps between concepts like culture and risk in the context of health literacy. First, the authors found that women with migration backgrounds (in the second generation) feel responsible not only for their own individual health, but also for the health of the whole family. In the context of health literacy and risk, similar familial and relational dimensions of the concept emerged both among participants with migration and non-migration backgrounds (Lorke et al. 2021a). Second, the role of intuition in the process of handling health information or decision-making is described as an important one among individuals with migration background(Adam und Carol 2020). In the context of risk and health literacy, intuition is also described as essential in the process of decision-making and information seeking regardless of the cultural backgrounds of the participants (Lorke et al. 2021a; Lorke et al. 2020; Lorke et al. 2021b). Third, Adam & Carol (2020) also thematise the complex informational situation of migrant women caused by the different channels of information in different languages. In the context of risk, the findings of the three included articles speak for a situation of similar complexity due to fast changing information environments concerning risk prediction.

Based on these three aspects, the following recommendations for health literacy promotion among migrants in the context of predictive and preventive medicine are made:

(1) Migration background in itself should not be seen as a determinant of health literacy: Bell et al. (2019) claim that promoting the idea of race as a determinant of individual risk may not only reflect, but also reinforce power inequities. Similar reasoning may be applied in the context of health literacy and migration background and needs to be critically questioned. E.g. Lorini et al. (2020) suggest that improving the population's health literacy may help mitigate health inequalities between residents and migrants. Their study offers a template for questioning the nature and quality of the differentiation between the health literacy of *residents* and *migrants,* inviting for critical discussions on the purpose and sense of such differentiation in the context of health literacy. Approaching health literacy as communicative action (Lorke et al. 2020) may be a way

of attending to migration background and ethnicity and at the same time avoiding the reinforcement of power inequalities.

(2) Labelling individuals with migration background or individuals at risk as *vulnerable* should not hinder participatory approaches. Studies on health literacy among members of vulnerable communities call for special considerations in the different research stages "in order to safeguard the integrity of the findings and the dignity of the participants themselves" (Morales 2017). In the context of risk, collaborative research on and promotion of health literacy is essential; researchers need to work out concepts and research designs which do not endanger the risk understanding of the participants (Lorke et al. 2021b), and which provide them with space to re-claim the power of the risk definition.

For society and research, such a culture-sensitive approach to conceptualising, living and promoting health literacy in the context of risk may be only beneficial. According to Douglas (1990) "the best way to stay cool about health and other hazards is to be self-aware about the choice between cultures" (p. 13). This claim is a good enough reason to call for more comparative anthropological research on issues of predictive and preventive medicine across the world.

3.1.5 HEALTH LITERACY IN THE CONTEXT OF RISK AS PREVENTIVE PRACTICE - PARTICIPATION AND DISTRIBUTION OF BLAME

Labelling people as vulnerable due to an increased health risk in terms of statistical or medical data, or due to 'deficient' health literacy may hinder their participation in the health system and in taking care of their individual health. From a theoretical point of view, the label of vulnerability may also be seen as a social construct and classification system, and risk as a forensic resource[G] (Douglas 1990) which ensures that boundaries between moral and political categories in certain societies or groups are built and maintained (e.g. participating in health risk prediction as a sign of responsible and socially desirable behaviour and attitude; non-participating as non-responsible, non-informed and socially non-desirable). Elaborated from an anthropological point of view, we may consider two categories of vulnerability which regulate a society's dealing with foreignness (Schneider und Platenkamp 2019): (a) those labelled as vulnerable due to differences in the state of their (system or medical) knowledge (in the context of health literacy); (b) those labelled as vulnerable due to the consequences of *being at risk* for a person's identity and lifeworld (in the context of health risk prediction). Such categories may reinforce a hierarchical communication order, when competing definitions of risk and health

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[G] Especially in terms of "holding persons accountable" for undesirable outcomes (Douglas 1990).

fail to be balanced through: (a) the communicative relationship between doctors and advice seekers, (b) increased awareness of vulnerability on a systemic level, or (c) empowerment-oriented research and health literacy promotion. On a practical level this missing balance may lead to the attribution of blame or hinder participation.

The findings of the included articles demonstrate that in the field of risk prediction the concept of agency (as the capacity to act and make decisions independently in the context of individuals' health and risk) may be challenged with respect to health literacy. On the one hand, tensions between the individual's lifeworld and the system, as well as between communicative and strategic action, reveal the challenges faced by organisations and individuals enabling/requiring access to predictive health services and acting upon disclosure of a positive test result (Lorke et al. 2020). On the other hand, the idea of individual responsibility in the context of risk prediction and *knowing about the risk* may reinforce the feeling of blame - for not being successful enough in prevention in the case of disease breakout in the field of mental health (Lorke et al. 2021b), or provoking the cancer emergence due to self-fulfilling prophecy in the case of genetic testing (Lorke et al. 2021a). In the context of health literacy and risk, individuals' agency is challenged both on an organisational and individual level.

Views on the self as being at risk and on one's individual role in the health-relationship have an impact on how health and disease are experienced and handled (Betsch et al. 2016). This subjectivity may be easily overlooked in the field of health literacy which follows a universalistic approach to risk and health literacy. Ignoring the cultural values behind the concept of health literacy may lead to labelling a group of people as 'deficient' and thereby missing the chance to integrate that group's resources into the health system. There is some evidence in other fields of the health sciences which demonstrates the consequences of such a universalistic attitude towards health values, and which emphasises the importance of sensitivity towards diversity in medical care (Ingleby 2012; Kidd et al. 2018). According to Bruchhausen (2017) this means that not only the culture of the group, but also the culture of each single individual should be considered in intercultural communication in a medical context. Thus, one might recommend avoiding any attempt to work out culture-specific definitions and dimensions of health literacy. Put into practice in highly diverse societies, this would mean avoiding study designs which address a group of individuals as vulnerable solely based on their migration background or nationality.

Ingleby (2012) encouraged his readers to reflect on the moral and political dimensions of health literacy, on the health care system as a guardian of values, and on the "dangerous kind of arrogance" which assumes that only Western health understandings may be considered literate. In the same vein, risk in health is also becoming increasingly political and controversial and implies a high degree of classification work (referring to Foucault's (1990) notion of biopolitics). Classification in this sense does not only happen at the clinical and administrative level of the health system, but also in a political and identity-forming dimension (von Unger et al. 2016). As a consequence, health literacy research and practice in the context of risk have a highly symbolic and social responsibility, and therefore need to constantly reflect on their function as a mechanism of power and control.

3.2 PRACTICAL IMPLICATIONS: A MODULE-BOX

The synthesised findings from the included articles and their discussion above offer a range of recommendations addressing the communication of risk between advice-seekers and their doctors. One possible way of getting closer to real-life practical implications is to suggest a guide for the development of units for professional education and training. In the following module-box, the theoretical recommendations for research and practice were transformed into anchor points for training sequences in the field of patient-doctor communication in predictive and preventive medicine. The innovative potential of this module-box lies in the fact that (1) it grounds in empirical findings of a study on persons at risk of developing certain diseases, (2) it emphasises a bottom-up perspective, and (3) it offers anchor points for the development of culture-sensitive counselling practice through professional education and training.

Module-box for the development of culture-sensitive communication trainings in the field of predictive and preventive medicine

What?

This module-box is grounded in empirical findings in a study on persons *at risk* of developing certain diseases. It offers anchor points for the development of culture-sensitive consultancy practice through professional education and training emphasising the patient perspective.

Who?

This tool may be helpful for professional trainers and coaches who work in the field of doctor-patient communication and require a set of methods and sequences, which may be used for the development of training units in the context of risk prediction and prevention.

How to use the module box?

This module-box is intended to guide the development of training sessions on patient-physician communication in the field of predictive medicine. It is designed for professional trainers and coaches and does not provide ready-to-use concepts. Rather, it offers points of orientation that can be individually adapted and further developed for the specific target group. Since the module-box claims a culture-sensitive approach, fundamental knowledge on patient-centeredness, diversity and cultural awareness is essential for the applicability of the tool.

Patient-driven themes:	Education goals:	You need methods and simulations which:
Health literacy and risk – a communicative action The consultation encounter can be seen as (1) the space in which health literacy and risk understanding are being constructed and negotiated, and as (2) an intercultural encounter including different risk and health understandings, role-expectations and strategies to handle the feeling of uncertainty and trust.	increasing awareness of: - strategic communication - communication filters (Scrimshaw 2018)	- demonstrate differences between communicative action and strategic communication - increase awareness of possible cultural misunderstandings - increase knowledge of an individual's lifeworld and its impact on the communication filters in the risk communication
Narratives on risk and health The way of narrating risk in everyday life, in medical practice or while doing research is crucial both for (1) the ways risk is perceived and lived by the so-called *persons at risk,* and for (2) a better understanding of how risk is contextualised and classified in a specific environment.	increasing sensitivity to: - narratives on/for risk understanding and coping - blurred border between risk and disease	- target and increase awareness of the different stages of the process of handling risk (decision-making, integrating the knowledge about risk in everyday life, and identity) and not solely emphasising the stage of risk understanding
Health as a journey, experiences and values Since individuals interpret risk information in the framework of their individual experiences, values and emotions, a certain risk prediction may affect the process of identity construction and impact life-planning (e.g. genetic testing) or personality (e.g. in the field of mental health).	sharpening sensitivity to: - patients' risk explanation models	- emphasise the importance of identity in the process of risk prediction and prevention - explicitly address subjectivity during the risk communication between professionals and patients in order to make possibly competing values visible (in terms of lifeworld)
Vulnerability and diversity Vulnerability needs to be taken into account:(1) in the context of strategic communication, and (2) in terms of the individual's identity and lifeworld. Approaching health literacy and risk in a culture-sensitive manner in highly diverse societies requires paying special attention to ethnicity and migration background.	increasing awareness of: - epistemic injustice - vulnerability through familial responsibility	- demonstrate the importance of the different facets of risk understanding (not only in mathematical terms) - develop strategies for handling the issue of "telling the family" - offer insights into participatory approaches on risk and health - increase knowledge of migration background as a factor in risk communication
Blame and responsibility In the field of risk prediction, the concept of agency may have an ambivalent role with respect to health literacy – knowing about the risk does not necessarily lead to a sense of agency and gain of control. Health literacy in the context of risk has a high symbolic, social and inclusion responsibility, and needs to constantly reflect on its own function as a mechanism of power and control.	increasing awareness of: - ethno-centrism - mechanisms of power - self-blame and responsibility	- enable reflection on the moral and political dimensions of health literacy in the context of risk - encourage intercultural comparison of risk understanding and management around the world

3.3 STRENGTHS AND LIMITATIONS

The design of the current PhD thesis is subject to some limitations related to (1) methodology of sampling and data collection, (2) the researcher's role in the process of data collection and analysis, and (3) the research environment. Nevertheless, some of the indicated limitations may be also seen as strengths and potentials depending on the context of interpretation.

(1) *Methodology of sampling and data collection*: First, the study is based on empirical data from a limited number of interviews. Thus, due to the sample size and the qualitative study design, the findings of this study mainly reflect the experiences and thoughts of the involved individuals and cannot be generalised for a large number of social groups. Otherwise, the strength of such a qualitative approach lies in the depth of the collected data which allows insight into complex topics grounded in real life experiences. Second, the participants who consented to engage in the interview process can be assumed to share a relatively high interest in health topics and are not representative for all social layers and ways of life. It will be interesting to explore the themes of the current study in collaboration with individuals with heterogeneous socioeconomic backgrounds who have a low interest in health matters. A recommendation for future research is to consider purposive sampling in order to address this heterogeneity, even though such an approach may entail difficulties in recruiting and make research more time consuming. Third, the cultural background (in its most popular meaning based on nationality or ethnicity) was not explicitly addressed in the phase of study design and recruiting. In the field of health sciences, this decision may be considered as uncommon when focusing on a culture-sensitive approach. On the other hand, in the field of ethnology and social anthropology (and in interdisciplinary academic communities (cf. Napier et al. 2014)), this decision may be seen as a strength since it embraces the recommendations of a wider understanding of culture in the context of health.

(2) *The researcher's role in the process of data collection and analysis:* Since the key topic of this thesis is related to culture, in terms of transparency it is necessary to mention the author's cultural perspective. Indeed, the author's migration background may have influenced the analysis and the interpretation of the study results. Due to training in methods of ethnological research, this potential bias was an object of (self-) analysis and constant reflection throughout the whole research process. Such reflection is recommendable for every researcher regardless of the specific cultural or academic background.

(3) *Gender, class and religion:* Qualitative explorative research calls for reflections on phenomena related to gender, class or religion and their impact on health literacy and risk. Furthermore, in the case of this project all researchers involved in the empirical phase are female. Since this research has a limited scope and is influenced by the framework of the underlying scientific project, a reflection on these concepts was not included in this thesis. Nevertheless, a recommendation for future research is to embed these dimensions in the research and analytical processes.

(4) *The research environment:* Due to the specifics of the research field – predictive and preventive medicine – and the collaboration with clinical partners, the recruiting of study participants led to the exclusion of individuals with a subjectively perceived, but not medically confirmed risk. Furthermore, solely the risk perceptions of persons at risk were the object of research and not those of health care professionals. This may be interpreted as a strength in the context of both patient-centeredness and participatory research. However, from a theoretical perspective, doctors' individual attitudes, understandings and interpretations of health literacy and risk are as important as those of patients. Since their perspective was not part of the underlying project (RisKomp), follow-up research on this topic was initiated on an individual basis[H]. For future research on risk and health literacy, a combined study design addressing both doctors and patients may be beneficial.

5. CONCLUSION

Bröckling (2017) describes prevention as an elementary mode in which contemporary societies negotiate their relation to the future, and as a cultural pattern that includes discourses as well as social practices and material artefacts (p. 74). In order to address risk in the context of preventive medicine it is essential to be aware of this "cultural pattern", and to make it both tangible for the purposes of health communication and beneficial for a diversity-sensitive health system. This cultural pattern surrounding the concept of risk in medicine also has a substantial impact on health literacy on an individual and organisational level. The current PhD thesis addressed these cultural dimensions of health literacy and risk from the perspective of individuals *at risk,* and illuminated the factors which on the one hand constitute their individual lifeworlds, and on the other hand underpin the potentials of a culture- sensitive approach to health literacy and risk in the context of predictive and preventive medicine.

[H] In the context of the doctoral project of Laura Harzheim, M.Sc., under the supervision of Prof. Dr. Dr. Saskia Jünger, additional qualitative data was collected by means of narrative interviews with experts in the field of risk prediction and participant observation. The study focuses on shared decision making.

The novelty of the thesis lies in the design of the qualitative research which combines anthropological and health sciences approaches. Furthermore, the work addressed the concepts of health literacy and risk in a culture-sensitive approach both on a *methodological* and *content* level, and provided a theoretical foundation of empirical data, as well as a practical orientation for researchers and practitioners. This transformation of theoretical ideas and interpretations merged into a module-box which can be used by professionals in the field of education and training.

The included contributions illuminated three spheres of the influence of risk prediction and negotiation: communication (Lorke et al. 2020), body (Lorke et al. 2021a) and mind (Lorke et al. 2021b). Gaining more understanding of individuals' explanatory models of risk and health in the context of their lifeworlds adds one additional layer of understanding risk in medicine which needs to be reflected on. That is why the conceptualisation and operationalisation of health literacy in the context of risk both in research and in preventive and predictive practice may benefit from a conscious culture-sensitive approach. Approaching risk counselling as an intercultural encounter may increase awareness of the different cultural embeddings of risk and the narratives that define them, and improve communication skills. Furthermore, sharpening sensitivity for the various cultural embeddings of risk in health also contributes to increased critical health literacy as well as to a broader critical approach to risk and health literacy in terms of the distribution of power and blame. With respect to future research on health literacy and risk addressing culture in a narrower sense (in terms of nationality, ethnicity, or migration background) this thesis also invites for re-negotiating the concepts of vulnerability and offers practice-oriented recommendations for approaching the concepts in diversity-sensitive contexts.

Finally, I'd like to include a statement from an interview with a woman at risk of developing familial breast-ovarian cancer. Her words illustrate the entanglement of theoretical considerations, lifeworld and explanatory models, health literacy and vulnerability. When asked how she would describe her knowledge of the risk, she answered: "As an angel on the shoulder, who says to be careful".

6. REFERENCES

Adam, Y., & Carol, S. (2020). *Gesundheitskompetenz von Menschen mit Migrationshintergrund: Perspektive und Erfahrungen von türkisch- und russischsprachigen Frauen*. Univ. Bielefeld, Interdisziplinäres Zentrum für Gesundheitskompetenzforschung (IZKG).

Aldin, A., Chakraverty, D., Baumeister, A., Monsef, I., Noyes, J., Jakob, T., et al. (2019). Gender differences in health literacy of migrants: a synthesis of qualitative evidence. *Cochrane Database of Systematic Reviews*.

Aronowitz, R.A. (2009). The converged experience of risk and disease. *The Milbank quarterly, 87*(2), 417–442.

Barton, A.J., Allen, P.E., Boyle, D.K., Loan, L.A., Stichler, J.F., & Parnell, T.A. (2018). Health Literacy: Essential for a Culture of Health. *Journal of continuing education in nursing, 49*(2), 73–78.

Beck, U. (1992). *Risk society: Towards a new modernity: translated by Mark Ritter.* London, Newbury Park, Calif: Sage Publications.

Bell, H.S., Odumosu, F., Martinez-Hume, A.C., Howard, H.A., & Hunt, L.M. (2019). Racialized Risk in Clinical Care: Clinician Vigilance and Patient Responsibility. *Medical anthropology, 38*(3), 224–238.

Betsch, C., Böhm, R., Airhihenbuwa, C.O., Butler, R., Chapman, G.B., Haase, N., et al. (2016). Improving Medical Decision Making and Health Promotion through Culture-Sensitive Health Communication: An Agenda for Science and Practice. *Medical decision making: an international journal of the Society for Medical Decision Making, 36*(7), 811–833.

Binder, P., Borné, Y., Johnsdotter, S., & Essén, B. (2012). Shared language is essential: communication in a multiethnic obstetric care setting. *Journal of health communication, 17*(10), 1171–1186.

Bizumic, B. (2018). *Ethnocentrism: Integrated perspectives.* London, New York, NY: Routledge.

Boholm, Å. (2003). The cultural nature of risk: Can there be an anthropology of uncertainty? *Ethnos, 68*(2), 159–178.

Bollars, C., Sørensen, K., Vries, N. de, & Meertens, R. (2019). Exploring health literacy in relation to noncommunicable diseases in Samoa: a qualitative study. *BMC public health, 19*(1), 1151.

Breuer, F., Muckel, P., & Dieris, B. (2017). *Reflexive Grounded Theory: Eine Einführung für die Forschungspraxis.* Wiesbaden: Springer Fachmedien Wiesbaden.

Bröckling, U. (2017). *Gute Hirten führen sanft: Über Menschenregierungskünste.* Berlin: Suhrkamp.

Bröder, J., Okan, O., Bauer, U., Bruland, D., Schlupp, S., Bollweg, T.M., et al. (2017). Health literacy in childhood and youth: a systematic review of definitions and models. *BMC public health, 17*(1), 361.

Bruchhausen, W. (2017). Ärztliches Handeln in kultureller Differenz – Was erwarten Menschen von der Medizin? Mecklenburg-Vorpommern, 6, 214-215. *Ärzteblatt Mecklenburg-Vorpommern, 6*, 214–215.

Carel, H., & Kidd, I.J. (2014). Epistemic injustice in healthcare: a philosophial analysis. *Medicine, health care, and philosophy, 17*(4), 529–540.

Castro, E.M., van Regenmortel, T., Vanhaecht, K., Sermeus, W., & van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient education and counseling, 99*(12), 1923–1939.

Chang, C.D. (2019). Social Determinants of Health and Health Disparities Among Immigrants and their Children. *Current problems in pediatric and adolescent health care, 49*(1), 23–30.

Chinn, D. (2011). Critical health literacy: a review and critical analysis. *Social science & medicine (1982), 73*(1), 60–67.

Davis, T.C., Long, S.W., Jackson, R.H., Mayeaux, E.J., George, R.B., Murphy, P.W., et al. (1993). Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Family medicine, 25*(6), 391–395.

Douglas, M. (1990). Risk as a Forensic Resource. *Deadalus, 119*(4), 1–16.

Douglas, M. (2002). *Purity and Danger: An Analysis of Concepts of Pollution and Taboo.* London: Routledge.

Durkheim, É. (1915). *"Deutschland über alles": Die deutsche Gesinnung und der Krieg.* Lausanne: Payot.

Evans-Pritchard, E.E. (1988). *Hexerei, Orakel und Magie bei den Zande.* Frankfurt am Main: Suhrkamp.

Farmanova, E., Bonneville, L., & Bouchard, L. (2018). Organizational Health Literacy: Review of Theories, Frameworks, Guides, and Implementation Issues. *Inquiry: a journal of medical care organization, provision and financing, 55*, 46958018757848.

Fiedler, S., Pförtner, T.-K., Nitzsche, A., McKee, L., & Pfaff, H. (2019). Health literacy of commercial industry managers: an exploratory qualitative study in Germany. *Health promotion international, 34*(1), 5–15.

Foucault, M. (1990). *Der Gebrauch der Lüste.* Frankfurt am Main: Suhrkamp.

Foucault, M. (2019). *Die Geburt der Biopolitik: Vorlesung am Collège de France, 1978-1979.* Frankfurt am Main: Suhrkamp.

Gunn, C.M., Bokhour, B., Parker, V.A., Parker, P.A., Blakeslee, S., Bandos, H., et al. (2019). Exploring Explanatory Models of Risk in Breast Cancer Risk Counseling Discussions: NSABP/NRG Oncology Decision-Making Project 1. *Cancer nursing, 42*(1), 3–11.

Habermas, J. (1981). *Theorie des kommunikativen Handelns.* Frankfurt am Main: Suhrkamp.

Hayes, B., Fabri, A.M., Coperchini, M., Parkar, R., & Austin-Crowe, Z. (2020). Health and death literacy and cultural diversity: insights from hospital-employed interpreters. *BMJ supportive & palliative care, 10*(1), e8.

Heibges, M. (2019). Waldarbeit. Praxis der medizinischen Stammbaum-Arbeit in der familiären Krebsberatung. *Curare, 42*(1/2), 31–47.

Henrich, J., Heine, S.J., & Norenzayan, A. (2010). The weirdest people in the world? *The Behavioral and brain sciences, 33*(2-3), 61-83; discussion 83-135.

Hinneburg, J., & Ellermann, C. (2020). Evidenzbasierte Risikokommunikation in der Gynäkologie und Geburtshilfe. In J. Wacker, M. Sillem, M.W. Beckmann, & G. Bastert (Hrsg.), *Therapiehandbuch Gynäkologie und Geburtshilfe* (15-25). Berlin, Heidelberg: Springer.

Hoydis, J. (2021). Literature and Interdisciplinary (Health) Risk Research: Of Boundary Objects, Thought Styles, and Narratives of Uncertainty. *Anglistik: International Journal of English Studies, 32*(3).

Hughson, J.-A., Marshall, F., Daly, J.O., Woodward-Kron, R., Hajek, J., & Story, D. (2018). Health professionals' views on health literacy issues for culturally and linguistically diverse women in maternity care: barriers, enablers and the need for an integrated approach. *Australian health review: a publication of the Australian Hospital Association, 42*(1), 10–20.

Huhta, A.-M., Hirvonen, N., & Huotari, M.-L. (2018). Health Literacy in Web-Based Health Information Environments: Systematic Review of Concepts, Definitions, and Operationalization for Measurement. *Journal of medical Internet research, 20*(12), e10273.

Hunt, L.M., Castañeda, H., & Voogd, K.B. de (2006). Do notions of risk inform patient choice? Lessons from a study of prenatal genetic counseling. *Medical anthropology, 25*(3), 193–219.

Ingleby, D. (2012). Acquiring health literacy as a moral task. *International Journal of Migration, Health and Social Care, 8*(1), 22–31.

Jenny, M.A., Keller, N., & Gigerenzer, G. (2018). Assessing minimal medical statistical literacy using the Quick Risk Test: a prospective observational study in Germany. *BMJ open, 8*(8), e020847.

Jordan, J.E., Buchbinder, R., & Osborne, R.H. (2010). Conceptualising health literacy from the patient perspective. *Patient education and counseling, 79*(1), 36–42.

Kidd, J., Black, S., Blundell, R., & Peni, T. (2018). Cultural health literacy: the experiences of Māori in palliative care. *Global health promotion, 25*(4), 15–23.

Kiechle, E.S., Bailey, S.C., Hedlund, L.A., Viera, A.J., & Sheridan, S.L. (2015). Different Measures, Different Outcomes? A Systematic Review of Performance-Based versus Self-Reported Measures of Health Literacy and Numeracy. *Journal of general internal medicine, 30*(10), 1538–1546.

Kilfoyle, K.A., Vitko, M., O'Conor, R., & Bailey, S.C. (2016). Health Literacy and Women's Reproductive Health: A Systematic Review. *Journal of women's health (2002), 25*(12), 1237–1255.

Kleinman, A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. *Social Science & Medicine, 12*(2-B), 85–93.

Koduah, A.O., Leung, A.Y.M., Leung, D.Y.L., & Liu, J.Y.W. (2019). "I Sometimes Ask Patients to Consider Spiritual Care": Health Literacy and Culture in Mental Health Nursing Practice. *International journal of environmental research and public health, 16*(19).

Konrad, M. (2003). Predictive genetic testing and the making of the pre-symptomatic person: Prognostic moralities amongst Huntington's-affected families. *Anthropology & medicine, 10*(1), 23–49.

Kostareva, U., Albright, C.L., Berens, E.-M., Levin-Zamir, D., Aringazina, A., Lopatina, M., et al. (2020). International Perspective on Health Literacy and Health Equity: Factors That Influence the Former Soviet Union Immigrants. *International journal of environmental research and public health, 17*(6).

Lein, I., & Jenny, M. (2020). Risikokommunikation bei der Krebsfrüherkennung: Risiken und Unsicherheiten erkennen und kommunizieren. *MTA-Dialog, 21*(2), 94–99.

Lengwiler, M., & Madarász, J. (2010). Das präventive Selbst.

Lévi-Strauss, C., & Heintz, S. (1955). *Traurige Tropen.* Köln: Kiepenheuer & Witsch.

Lorig, K. (2012). Patient-Centered Care: Depends on the Point of View. *Health education & behavior: the official publication of the Society for Public Health Education, 39*(5), 523–525.

Lorini, C., Caini, S., Ierardi, F., Bachini, L., Gemmi, F., & Bonaccorsi, G. (2020). Health Literacy as a Shared Capacity: Does the Health Literacy of a Country Influence the Health Disparities among Immigrants? *International journal of environmental research and public health, 17*(4).

Lorke, M., Harzheim, L., Rhiem, K., Woopen, C., & Jünger, S. (2021a). The ticking time-bomb. Health literacy in the context of genetic risk prediction in familial breast-ovarian cancer. A qualitative study. *Qualitative Research in Medicine & Healthcare, 5.*

Lorke, M., Harzheim, L., Woopen, C., & Jünger, S. (2020). Health Literacy as Communicative Action-A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine. *International journal of environmental research and public health, 17*(5).

Lorke, M., Schwegler, C., & Jünger, S. (2021b). Re-claiming the Power of Definition—The Value of Reflexivity in Research on Mental Health at Risk. In M. Borcsa & C. Willig (Hrsg.), *Qualitative Research Methods in Mental Health*: *Innovative and collaborative approaches* (S. 135–165). Cham: Springer.

Maddock, C., Camporesi, S., Lewis, I., Ahmad, K., & Sullivan, R. (2012). Online information as a decision making aid for cancer patients: recommendations from the Eurocancercoms project. *European journal of cancer (Oxford, England: 1990), 48*(7), 1055–1059.

Magnani, J.W., Mujahid, M.S., Aronow, H.D., Cené, C.W., Dickson, V.V., Havranek, E., et al. (2018). Health Literacy and Cardiovascular Disease: Fundamental Relevance to Primary and Secondary Prevention: A Scientific Statement From the American Heart Association. *Circulation, 138*(2), e48-e74.

Malinowski, B. (1999). *Argonauts of the western Pacific: An account of native enterprise and adventure in the archipelagoes of Melanesian New Guinea.* London: Routledge.

Matas, H., & Bronstein, J. (2018). A qualitative inquiry of old people's health literacy in situations of health uncertainty. *Health information and libraries journal, 35*(4), 319–330.

Mechanic, D., & Tanner, J. (2007). Vulnerable people, groups, and populations: societal view. *Health affairs (Project Hope), 26*(5), 1220–1230.

Messer, M., Vogt, D., Quenzel, G., & Schaeffer, D. (2015). Health Literacy bei Menschen mit Migrationshintergrund. *Public Health Forum, 23*(2), 121–123.

Morales, M. (2017). Health Literacy Research Methods. *International Journal of Qualitative Methods, 16*(1), 160940691770991.

Napier, A.D., Ancarno, C., Butler, B., Calabrese, J., Chater, A., Chatterjee, H., et al. (2014). Culture and health. *The Lancet, 384*(9954), 1607–1639.

Nutbeam, D. (2008). The evolving concept of health literacy. *Social science & medicine (1982), 67*(12), 2072–2078.

Nutbeam, D., McGill, B., & Premkumar, P. (2018). Improving health literacy in community populations: a review of progress. *Health promotion international, 33*(5), 901–911.

Okan, O., Rowlands, G., Sykes, S., & Wills, J. (2020). Shaping Alcohol Health Literacy: A Systematic Concept Analysis and Review. *Health literacy research and practice, 4*(1), e3-e20.

Paasche-Orlow, M.K., & Wolf, M.S. (2007). The causal pathways linking health literacy to health outcomes. *American journal of health behavior, 31 Suppl 1*, S19-26.

Palumbo, R. (2015). Discussing the Effects of Poor Health Literacy on Patients Facing HIV: A Narrative Literature Review. *International journal of health policy and management, 4*(7), 417–430.

Parisod, H., Axelin, A., Smed, J., & Salanterä, S. (2016). Determinants of tobacco-related health literacy: A qualitative study with early adolescents. *International journal of nursing studies, 62*, 71–80.

Parker, R.M., Baker, D.W., Williams, M.V., & Nurss, J.R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of general internal medicine, 10*(10), 537–541.

Petrova, D., Traczyk, J., & Garcia-Retamero, R. (2019). What shapes the probability weighting function? Influence of affect, numeric competencies, and information formats. *Journal of Behavioral Decision Making, 32*(2), 124–139.

Polzer, J. (2010). Caring for the self, caring for others. The politicas and ethics of generic risk for breast cancer. *Canadian woman studies, 28*(2, 3), 71–76.

Rheault, H., Coyer, F., Jones, L., & Bonner, A. (2019). Health literacy in Indigenous people with chronic disease living in remote Australia. *BMC health services research, 19*(1), 523.

Rikard, R.V., Thompson, M.S., McKinney, J., & Beauchamp, A. (2016). Examining health literacy disparities in the United States: a third look at the National Assessment of Adult Literacy (NAAL). *BMC public health, 16*, 975.

Rosenbrock, R. (2016). *Interkulturelle Öffnung und Gesundheitskompetenz Zwei Wege – ein Ziel.* Gesundheitspolitische Veranstaltung, GENO-Haus Stuttgart, 27. Juli 2016.

Rowlands, G., Shaw, A., Jaswal, S., Smith, S., & Harpham, T. (2017). Health literacy and the social determinants of health: a qualitative model from adult learners. *Health promotion international, 32*(1), 130–138.

Samerski, S. (2011). *Die Entscheidungsfalle: Wie genetische Aufklärung die Gesellschaft entmündigt.* Darmstadt: WBG - Wissenschaftliche Buchgesellschaft.

Samerski, S., & Henkel, A. (2015). Responsibilisierende Entscheidungen. Strategien und Paradoxien des sozialen Umgangs mit probabilistischen Risiken am Beispiel der Medizin. *Berliner Journal für Soziologie, 25*(1-2), 83–110.

Sarangi, S., Bennert, K., Howell, L., & Clarke, A. (2003). 'Relatively speaking': Relativisation of genetic risk in counselling for predictive testing. *Health, Risk & Society, 5*(2), 155–170.

Schaeffer, D., Hurrelmann, K., Bauer, U., & Kolpatzik, K. (2018). *Nationaler Aktionsplan Gesundheitskompetenz: Die Gesundheitskompetenz in Deutschland stärken*. Berlin. file:///C:/Users/mariy/Downloads/Nationaler%20Aktionsplan%20Gesundheitskompetenz.pdf. Zugegriffen: 19. März 2021.

Schaeffer, D., Vogt, D., Berens, E.-M., & Hurrelmann, K. (2016). *Gesundheitskompetenz der Bevölkerung in Deutschland: Ergebnisbericht*. Universität Bielefeld, Fakultät für Gesundheitswissenschaften.

Schneider, A., & Platenkamp, J.D.M. (2019). *Integrating Strangers in Society: Perspectives From Elsewhere.* Cham: Palgrave Macmillan Ltd.

Scholl, I., Zill, J.M., Härter, M., & Dirmaier, J. (2014). An integrative model of patient-centeredness - a systematic review and concept analysis. *PloS one, 9*(9), e107828.

Schröer, H. (2007). Interkulturelle Orientierung und Öffnung: ein neues Paradigma für die soziale Arbeit. *Archiv für Wissenschaft und Praxis der sozialen Arbeit*(3), 80–91.

Schütz, A., & Luckmann, T. (1979). *Strukturen der Lebenswelt.* Frankfurt am Main: Suhrkamp.

Scrimshaw, S.C. (2019). Science, health, and cultural literacy in a rapidly changing communications landscape. *Proceedings of the National Academy of Sciences of the United States of America, 116*(16), 7650–7655.

Shepherd, S.M. (2019). Cultural awareness workshops: limitations and practical consequences. *BMC medical education, 19*(1), 14.

Slovic, P., Finucane, M.L., Peters, E., & MacGregor, D.G. (2004). Risk as analysis and risk as feelings: some thoughts about affect, reason, risk, and rationality. *Risk analysis: an official publication of the Society for Risk Analysis, 24*(2), 311–322.

Sørensen, K., Pelikan, J.M., Röthlin, F., Ganahl, K., Slonska, Z., Doyle, G., et al. (2015). Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *European journal of public health, 25*(6), 1053–1058.

Sørensen, K., van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., et al. (2012). Health literacy and public health: a systematic review and integration of definitions and models. *BMC public health, 12*, 80.

Svendsen, M.N. (2006). The social life of genetic knowledge: a case-study of choices and dilemmas in cancer genetic counselling in Denmark. *Medical anthropology, 25*(2), 139–170.

Svendsen, M.T., Bak, C.K., Sørensen, K., Pelikan, J., Riddersholm, S.J., Skals, R.K., et al. (2020). Associations of health literacy with socioeconomic position, health risk behavior, and health status: a large national population-based survey among Danish adults. *BMC public health, 20*(1), 565.

Tennant, B., Stellefson, M., Dodd, V., Chaney, B., Chaney, D., Paige, S., et al. (2015). eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. *Journal of medical Internet research, 17*(3), e70.

Tones, K. (2002). Health literacy: new wine in old bottles? *Health education research, 17*(3), 287–290.

Vargas Pelaez, A.F., Ramirez, S.I., Valdes Sanchez, C., Piedra Abusharar, S., Romeu, J.C., Carmichael, C., et al. (2018). Implementing a medical student interpreter training program as a strategy to developing humanism. *BMC medical education, 18*(1), 141.

von Unger, H., Odukoya, D., & Scott, P. (2016). Kategorisierung als diskursive Praktik: Die Erfindung der „Ausländer-Tuberkulose“. In S. Bosanac & R. Keller (Hrsg.), *Perspektiven wissenssoziologischer Diskursforschung* (S. 157–176). [Wiesbaden]: Springer VS.

Wacker, J., Sillem, M., Beckmann, M.W., & Bastert, G. (Hrsg.) (2020). *Therapiehandbuch Gynäkologie und Geburtshilfe.* Berlin, Heidelberg: Springer.

Wolf, M.S., Bennett, C.L., Davis, T.C., Marin, E., & Arnold, C. (2005). A qualitative study of literacy and patient response to HIV medication adherence questionnaires. *Journal of health communication, 10*(6), 509–517.

Woloshin, S., Schwartz, L.M., Moncur, M., Gabriel, S., & Tosteson, A.N. (2001). Assessing values for health: numeracy matters. *Medical decision making: an international journal of the Society for Medical Decision Making, 21*(5), 382–390.

7. LEBENSLAUF

Mein Lebenslauf wird aus Gründen des Datenschutzes in der elektronischen Fassung meiner Arbeit nicht veröffentlicht.

8. EIDESSTATTLICHE ERKLÄRUNG

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Übersicht der Publikationen:

Lorke, Mariya*; Harzheim, Laura*; Woopen, Christiane; Jünger, Saskia (2020): Health Literacy as Communicative Action-A Qualitative Study among Persons at Risk in the Context of Predictive and Preventive Medicine. In: *International journal of environmental research and public health* 17 (5). DOI: 10.3390/ijerph17051718.

Lorke, Mariya*; Schwegler, Carolin*; Jünger, Saskia (2021): *Re-claiming the Power of Definition—The Value of Reflexivity in Research on Mental Health at Risk.* In: Maria Borcsa und Carla Willig (Eds.): Qualitative Research Methods in Mental Health. Innovative and collaborative approaches. Cham: Springer, pp. 135–165.

Lorke, Mariya*; Harzheim, Laura; Rhiem, Kerstin; Woopen, Christiane; Jünger, Saskia (2021): The ticking time-bomb. Health literacy in the context of genetic risk prediction in familial breast-ovarian cancer. A qualitative study. In: *Qualitative Research in Medicine & Healthcare* 5. DOI: 10.4081/qrmh.2021.9647.

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