

HEALTH EVIDENCE NETWORK SYNTHESIS REPORT 49

Cultural contexts of health: the use of narrative research
in the health sector

Trisha Greenhalgh



World Health
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HEN and the cultural contexts of health project at the WHO Regional Office for Europe

The project on the cultural contexts of health was initiated at the WHO Regional Office for Europe in response to the Member States' recommendation that the implementation of Health 2020 could be improved by a more thorough understanding of the cultural contexts of health in the highly diverse European Region. As a consequence, an expert group meeting on the cultural contexts of health and well-being was convened by the WHO Regional Office for Europe on 15–16 January 2015. The expert group recommended that current well-being and health reporting could be improved through the use of new types of evidence, particularly qualitative and narrative research from a larger variety of academic disciplines and from a wide array of cultural contexts. In order to test this recommendation, and to better understand how narrative research was currently being deployed in the health sector, this HEN synthesis report was commissioned.

Health Evidence Network synthesis report 49

Cultural contexts of health: the use of narrative
research in the health sector

Trisha Greenhalgh

Abstract

Narrative (storytelling) is an essential tool for reporting and illuminating the cultural contexts of health – that is, the practices and behaviour that groups of people share and which are defined by customs, language and geography. This report reviews the literature on narrative research, offers some quality criteria for appraising such research and gives three detailed worked case examples: diet and nutrition, well-being, and mental health in refugees and asylum seekers. Storytelling (and story interpretation) belongs to the humanistic disciplines and is not a pure science, although established techniques of social science can be applied to ensure rigour in sampling and data analysis. The case studies illustrate how narrative research can convey the individual experience of illness and well-being, thereby complementing (and sometimes challenging) epidemiological and public health evidence.

Keywords

NARRATION; HEALTH SERVICES RESEARCH – METHODS; RESEARCH DESIGN; HEALTH KNOWLEDGE, ATTITUDES, PRACTICE; CULTURE; DELIVERY OF HEALTH CARE; HEALTH POLICY

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CONTRIBUTORS

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Author

Trisha Greenhalgh
Professor of Primary Care Health Sciences, University of Oxford, Oxford,
United Kingdom

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External peer reviewers

Brian Hurwitz
Professor of Medicine & the Arts, Director of the Centre for Humanities and Health,
Department of English, King's College London, London, United Kingdom

Maria Giulia Marini
Epidemiologist and Counsellor, Director of Health Care Area, Fondazione
ISTUD, Milan, Italy

WHO Regional Office for Europe

Division of Information, Evidence, Research and Innovation

Nils Fietje, Cultural Context of Health



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Claudia Stein, Director

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SUMMARY

The issue

The WHO Regional Office for Europe initiated a values-based approach in Health 2020 that seeks to enhance traditional, quantitative epidemiological forms of evidence by the use of narrative approaches that can take account of cultural contexts and help in the creation of people-centred health systems. An evidence base is needed on how narrative methods can add value to more conventional forms of health information.

The synthesis question

This report has examined narrative and its link to culture, use of narrative research to capture shared values and meaning systems of groups of people, the strengths and limitations of such an approach, and how narrative research could be used in health policy and planning in order to address the following question. How has qualitative evidence from narrative research been deployed in the health sector and used in influencing health policy?

Types of evidence

A methodological approach known as hermeneutic review was used to examine historical evidence on the emergence of narrative research in health care; methodological evidence on different approaches to, and quality criteria for, narrative research; and empirical evidence from a wide range of narrative studies that report and illustrate cultural contexts of health. These include clinical case reports, narrative interviews, ethnographies, photo-elicitation studies and discourse analyses.

Findings

A narrative (story) is a subjective version of events, told to a listener or reader. Narrative research includes the gathering of new stories, the collation and re-analysis of existing stories, the use of ethnography to study enacted stories, the construction of organizational or community case studies, and the study of policy as discourse. Narratives can complement other forms of evidence but must be collected and analysed with careful attention to quality. A set of key criteria



to guide critical appraisal of narrative research is proposed; these criteria include measures to assure trustworthiness, plausibility and criticality.

While listening to patients' stories has long been a key element of clinical medicine, the use of narrative research to enhance the understanding of cultural contexts of health is more recent. Narrative research has both strengths (e.g. stories are sense-making devices characterized by nonlinearity, fluidity, memorability and capacity to convey the perspective of the disadvantaged) and limitations (e.g. stories are not true in any direct sense and are open to multiple interpretations). Narrative research holds great promise for reporting and illuminating the cultural contexts of health and three case studies are chosen to illustrate this.

The first case study considers diet and nutrition and distinguishes between nutrition's two cultures: the post-swallowing world of biology, physiology, biochemistry and pathology (widely studied by scientists) and the pre-swallowing world of behaviour, culture, society and experience (sometimes overlooked by health researchers). People usually eat food because it has meaning for them rather than for its nutritional value. Those who seek to influence a community's eating patterns must engage with the social and cultural aspects of why, when and with whom people eat the foods they do.

The second case study concerns the measurement of well-being, which has until recently been dominated by quantitative metrics derived from survey questions. Narratives of well-being can be used both in mixed-methods research (to inform and refine the design of survey items) and in their own right (to add meaning, context and granularity to survey data).

The third case study addresses mental health in refugees and asylum seekers. A narrative approach can illuminate the dramatic and often tragic life experiences of the displaced in a way that may be missed (and even obscured) by the use of conventional medical and psychiatric categories – both at an individual level and in relation to the diasporas of cultural groups.

Policy considerations

The appropriate and rigorous use of narrative methods should be encouraged when assessing and reporting on the cultural contexts of health because their use alongside more traditional methodologies could support a more values-based

approach that is better able to incorporate (and respond appropriately to) diverse cultural contexts. Specific areas where narrative research could support health care options include:

- in combination with more traditional measures of population health status to produce cross-country comparisons for health issues that are strongly influenced by cultural contexts;
- to understand people's health-related experiences and lifestyle choices; and
- to inform the design and evaluation of interventions aimed at influencing such experiences and choices.

Since inappropriate and/or unrigorous use of narrative could distort rather than illuminate such reports, researchers should be trained in narrative research methods. WHO should, therefore, also consider developing training materials and workshops in order to integrate narrative methods into its existing capacity-building activities related to evidence-informed policy-making.



1. INTRODUCTION

1.1. Background

In 2014, the Lancet published a landmark report entitled "Culture and health" (1). Defining culture as "a set of practices and behaviours defined by customs, habits, language, and geography that groups of individuals share", the authors acknowledged that while much progress in medicine had been made as a result of epidemiological and basic science research, the lack of systematic attention to culture was a significant deficiency. They made a number of recommendations, including that medicine should accommodate the cultural construction of well-being, that culture should be incorporated in health and health care provision and that agency (i.e. human intention and action) should be better understood with respect to culture.

In January 2015, in response to a call from Member States looking to improve implementation of Health 2020 in the highly diverse WHO European Region (2), the WHO Regional Office for Europe convened an expert group to consider how better to incorporate cultural contexts into its work (3).

This Health Evidence Network report, commissioned on the advice of the expert group, addresses how qualitative evidence from narrative research has been deployed in the health sector and to what effect. Four specific areas were considered.

- What is narrative and what is its link to culture?
- How might the shared values and meaning systems of groups of people be captured using narrative research?
- What are the strengths and limitations of a narrative approach for researching the cultural contexts of health?
- How might narrative research be used in health policy and planning and what are the implications for future research by WHO and others?

The report contains two main elements: a summary and synthesis of narrative research methods and three case studies to illustrate the range of narrative approaches and how these can complement other data. The case studies examine cultural aspects of nutrition, the cultural context of well-being, and mental health in refugees and asylum seekers.

1.2. Methodology

This report used a novel methodological approach known as hermeneutic review (see Annexes 1 and 2) in order to examine the use of narrative approaches in health issues (see Annex 3). It was clear from the outset that an overly technocratic approach, while superficially rigorous, could overshadow the crucial process of interpretation and judgement. As Boell and Cezec-Kecmanovic have noted, "highly structured approaches [to systematic review] downplay the importance of reading and dialogical interaction between the literature and the researcher; continuing interpretation and questioning; critical assessment and imagination; argument development and writing – all highly intellectual and creative activities, seeking originality rather than replicability" (4).

1.2.1. Sources for this report

Sources were identified by starting with a small selection of books and papers widely recognized as seminal in the field (5–11) and then using various techniques (citation tracking, searching references of references) to expand from these while applying progressive focusing to limit the dataset (see Annex 1). Case studies were selected in discussion with WHO and sources obtained by the search strategy outlined in Annex 1.

1.2.2. Data extraction

Data extraction followed an interpretive rather than technical approach, with the goal of producing a rich understanding of each topic and data were combined and summarized using narrative synthesis. Much relevant material was omitted to achieve the required succinct format. This report has been extensively referenced to enable readers to pursue subtopics in more detail.



2. FINDINGS

2.1. Narrative research methods in health care

2.1.1. What is narrative?

Mary Piper said, "People attend to, remember, and are transformed by stories" (12). A narrative (story) is an account with a beginning, a sequence of unfolding events and an ending (8). It puts characters, events, actions and context together so as to make sense of them, and it generally follows a recognizable form and pattern (e.g. novel, myth or clinical case).

Even when based on real events, no story is an objective version of the truth (although importantly, the same might be said of a set of numbers or survey responses). Stories are *subjective* in that they convey one person's (or sometimes, a collective) version of events using a particular choice of words, metaphors and styles. Stories are also *intersubjective* (i.e. they connect to, and respond to, the subjectivities of their reader(s) and listener(s)) and are embodied in institutional and social practices. One person's story, told twice, is never the same. Different people tell different stories about the same event.

For all these reasons, stories must be handled carefully when collected and used as research data. However, used appropriately, stories can complement more conventional forms of research.

Psychologist Jerome Bruner distinguished two forms of human cognition: logicoscientific (which seeks to understand observed events in terms of generalizable truths and the laws of science) and narrative (which seeks to understand them in terms of human experience, meaning-making and purpose) (13), although he made this distinction before narrative research came to be recognized as legitimate social science.

Stories convince not by their objective truth but by their likeness to real life and their emotional impact on the reader or listener, which is achieved through literary features such as genre (e.g. comedy, tragedy and melodrama), metaphor (one thing is made more meaningful or vivid through subjective comparison with something else), aesthetic appeal (the story rings true to a particular audience) and moral order (heroes get their just rewards, villains their punishment).

Early writers on narrative focused on structure (narrative as noun). Aristotle, for example, proposed that a story has three key characteristics: chronology (unfolding of events and actions over time, although not always in an orderly sequence), emplotment (rhetorical juxtaposition of these events and actions using literary devices such as metaphor and suspense to evoke meaning, motive and causality) and *peripeteia* (trouble, the unexpected or twists in the plot) (14).

In recent decades, narrative scholars have focused more on the act of storytelling (narrative as verb) (15). They have sought to explore the circumstances of the telling and the shaping of a story through the interaction of the teller/writer and the reader/listener (real or imagined). Asking why *this* person has told *this* story in *this* way to *this* audience (or indeed, why someone has *not* told a story in a particular setting) may provide important insights, for example about the societal constraints on vulnerable groups in an unequal world.

2.1.2. Narrative research in health care: study designs and quality criteria

The practice of medicine depends on the clinical case history: a unique story about an individual patient that resonates (to a greater or lesser extent) with generic patterns or scripts of how diseases affect people (16). The history of narrative research in health care is described in Annex 3. It includes a number of distinct genres and study designs, including:

- traditional clinical case study, which is a clinician's reflections on a real clinical case (told from the perspective of the clinician);
- individual accounts of illness, captured through qualitative interviews;
- case study narratives of a health care organization or system that forms the institutional context for individual illness experience and treatment;
- cultural–historical narratives within which particular illness stories are embedded (e.g. the meta-narratives of disadvantaged and/or displaced communities);
- policy discourses (particular framings that drive action or justify inaction);
- the social drama of participatory research; and
- the shared, multivoiced narratives of online communities and social movements.

The criteria below are based on, and extend, an international research study to develop consensus quality criteria for narrative research in health care, originally published in 2008 (17). Note that not all qualitative research involves collecting, analysing or constructing stories and not all stories count as research.

- 
1. The use of narrative approaches counts as research if it is undertaken as systematic, focused enquiry with the explicit intention of furthering a body of knowledge (17). The aim of such research is not to determine a true picture of events but to explore such things as how an individual or group has made sense of these events (17).
 2. Narrative research may include one or more of the following activities (17):
 - story gathering, involving the collection of stories that have already been told or written for a different purpose (e.g. blogs, complaint letters and books);
 - story eliciting, where participants are asked to tell a story for the specific purpose of research, using one of the established methodologies for narrative interviewing (10,18–20);
 - observing the enactment of real life using real-time stories (e.g. using ethnography to observe events and interactions (21));
 - story interpreting, where a sample of stories are analysed or re-analysed using an explicitly narrative approach in order to draw meaning and develop theory (10,20,22);
 - constructing an organizational or community case study (20,23); and
 - analysing the storyline of a text using discourse analysis (24).
 3. Narrative research must meet the general criteria of high-quality research (17), including:
 - originality, clarity and importance of the research question;
 - appropriateness of the study design to answer the research question;
 - sample size and representativeness (although note that a maximum variety sample selected to incorporate a range of viewpoints may be more appropriate than a statistically representative one);
 - robustness of the data collection process, including choice of instruments or tools, experience and training and supervision of research staff;
 - quality and transparency of the analysis (including coherence of theoretical framework and an identifiable unit of analysis);
 - extent to which conclusions are justified by findings; and
 - awareness of the possibility of error and steps taken to minimize or take account of this throughout the research process.
 4. Rigour in narrative research is less about technical procedures (e.g. ensuring that two observers independently check the data) than about producing a convincing interpretation. In addition to the generic criteria of good research listed above, rigour is demonstrated through evidence of the following (25,26):

- trustworthiness, where researchers go beyond a superficial approach to collecting data (through measures such as prolonged engagement, triangulation and seeking disconfirming cases) to provide rich detail (what anthropologists call thick description) and include a cycle of member checking by research participants;
 - plausibility (verisimilitude), where researchers, in their account, are able to "recruit the reader ... smooth contestable assertions, build dramatic anticipation, and differentiate the findings" (26); hence the account rings true and allows the audience to enter the world of the research subject(s); and
 - criticality, where the researchers show a high degree of reflexivity, questioning their own findings and considering alternative interpretations for them.
5. Storytelling (and story interpretation) belongs to the humanistic disciplines and is not a pure science. However, scientific linguistic methods can be applied in the collection and interpretation of the text. The storyteller might use rhetoric and other literary devices to give a version of events from his or her own perspective. In narrative research, the story should, therefore, be anchored in some way (17), for example by:
- collecting multiple stories about the same event or comparable experiences;
 - linking the story to other sources of empirical data (e.g. biomedical data about the severity and time course of a person's illness); or
 - including a thorough and critical review of relevant literature.
6. Ethical duties arise for those who collect and use the stories of others (17,27). Requirements of the researcher role include:
- honesty in being explicit and transparent about the purpose of the research;
 - non-maleficence, that is intending to do no harm (unless balanced by a greater benefit);
 - obtaining consent and undertaking only those activities to which the storyteller has consented; and
 - confidentiality and protecting the identity of the storyteller (if that is his or her desire) and those implicated in the story.

While anecdote is rightly placed at the bottom of the evidence hierarchy in evidence-informed medicine, narrative research should not be equated with anecdote (28) any more than quantitative data should be equated with truth. Epidemiological studies and trials help us to make predictive statements about the frequency of events in populations and the likelihood of particular outcomes; narrative research helps us to make sense of experience. Both can be done well or badly and produce findings that are more or less trustworthy.



The false dichotomy between evidence-based and narrative-based medicine was dismissed in the late 1990s (28). Local and national contexts and issues affect the kind of research questions that are relevant to particular policy decisions and how evidence can or should be applied in practice (29,30). Policy-makers, consequently, require a wide range of evidence (31). As the case studies below illustrate, rigorously conducted and analysed narrative research can complement the findings of randomized trials, observational studies and routinely collected data of various kinds; inform new hypothesis-driven studies and refinement of survey instruments; explain the failures and partial successes of past policy initiatives; and inform the introduction and implementation of new policies.

It is clear that narratives may complement other forms of evidence, but these narratives must be collected and analysed with careful attention to quality. The above criteria may serve as a guide to critical appraisal of narrative research.

2.1.3. Potential strengths of narrative approaches

The grand challenges facing health care and related fields (e.g. social care or environmental risks) demand an extended range of methodologies for both research and evaluation (32). This section considers the strengths of using a narrative approach.

Stories are *sense-making* devices. They enable people to look back and make their lives (and illnesses) meaningful by retrospectively structuring events and actions in a way that conveys perceived causality (X happened because of Y); for example, "I've been drinking heavily since I got married" (13).

Stories are inherently *nonlinear* (they depict events as emerging from the interplay of actions, relationships and contexts), hence are particularly powerful tools for making sense of complex, emergent phenomena (such as a set of medically unexplained symptoms). As Charon has observed (27),

Narrative makes its own paths, breaks its own constraints, undercuts its own patterns. ... [It] can make new out of old, creating chaos out of linearity while, subversively, exposing underlying fresh connections among the seemingly unrelated.

Stories are often *evocative* and *memorable*. They are image rich, action packed and laden with emotions (8). Most people recall them better than they recall lists, graphs or numbers. Stories can convey important elements of nuance, including

mood, tone and urgency. We learn through stories because the story form allows our existing schemas (mental models of reality) to be modified in the light of emerging experiential knowledge (13). Indeed, stories are the unit of clinical memory (16) and, when making choices, the unit of decision-making (33).

Stories are necessarily *perspectival* (i.e. conveying a particular perspective). They are told from a particular person's (or cultural group's) point of view and provide unique and nuanced insights into that person's (or group's) lifeworld and how they interpret it (34).

Stories can capture *tacit knowledge*. In health care organizations, for example, they can bridge the gap between explicit, codified and formal knowledge (e.g. job descriptions, guidelines and protocols) and informal, uncoded knowledge (knowing how to get things done in a particular organization or team, sometimes referred to as knowing the ropes) (35,36).

Stories are *rhetorical*. Indeed, a story is a tool of argumentation, designed to persuade the listener of the legitimacy of the narrator's perspective. A patient's story may emphasize, for example, compliance with a medication regimen (therefore is a good patient). Narratives can support and enlarge upon other sources of evidence (e.g. a quality-of-life scale).

Individual stories are *nested within wider meta-narratives* (37) and thus provide a window for studying organizations, communities and cultures. As Case study 3 below illustrates, refugees' narratives capture "a shared past experience of separation, loss, physical hardship, discrimination, poverty, and persecution, all of which may be crucially important influences upon the nature and course of the illness" (38).

Stories have an *ethical dimension*. Many involve an underdog (someone who is poor, weak, sick, unlucky, disempowered, badly treated – or ineligible for basic health care). The person who reads or hears such a story incurs a duty to act so as to heal the sick, relieve pain, comfort the sad, protect the vulnerable or redress social injustice.

Stories are *open-ended*. They create possibilities through what Byron Good has called subjunctivization (39). By imagining a different ending – or indeed, a different beginning – to the story, a person (clinician, researcher, policy-maker) can explore what might have been, what could be, what should be and so on. Critical and near-miss events, for example, prompt the question "what could have been done differently to prevent this event?"



Finally, stories are *subversive*. As Bruner observed, "All stories involve a tension between the canonical and the unexpected" (13). Researchers examining organizations have distinguished between the official stories of success and progress told by top management (e.g. in annual reports and mission statements) and the counter-narratives told by front-line staff or patients (40,41). A story may support the role of the organizational-change agent who seeks (often for good reason) to subvert the existing system.

2.1.4. Potential limitations of narrative approaches

Notwithstanding the benefits of a narrative approach, there are some significant limitations.

First and foremost, narratives are not true in any simple sense. Norman Denzin, one of the world's leading authorities on qualitative research, has defined narratives as "fictional statements that, to a varying degree, are about real lived lives" (42). However, stories can be thought of as perspectival (i.e. conveying a particular perspective) rather than biased (i.e. systematically distorted), although they can sometimes be both. Whereas the term bias is used in epidemiology and has negative overtones, the term perspectival in narrative research has positive overtones since it allows access to a person's feelings and lifeworld. Nevertheless, if personal stories are equated with truth, this will produce impoverished research.

The story (anecdote) is – often rightly – classified as a weak form of evidence. The temporal nature of the narrative form often implies causality (as in "I got married and [then] started drinking heavily") but in reality the story may highlight an incidental or confounding factor rather than a true underlying cause. Narrative accounts are never self-interpreting. As Marita Eastmond has observed (43):

[A]n experience is never directly represented but edited at different stages of the process from life to text. As published text, the story is exposed to a different audience and to further interpretation. Culture is thus central ..., not only in the making of a meaningful story by a particular subject, but also in the ways that others understand and retell the story.

Both the ability to narrate stories and what have been called storytelling rights (44) are unevenly distributed in society. It is the educated, articulate and culturally enriched who tell stories through novels, speeches, blogs and so on – and who are usually over-represented in research samples.

The institutional contexts in which research is undertaken may constrain and distort the stories told. In a study of patients' experiences of interpreting services, participants told positive stories about their experience with the service when professional interpreters were used to facilitate focus groups (45), but a new theme emerged of deep unease with the official interpreting service when facilitators were provided by a voluntary sector health advocacy organization.

Some narratives simply cannot be told, perhaps because the individual has lost the ability to narrate (e.g. through injury or severe dementia), has been so profoundly traumatized that their story is suppressed or may find the task of narration too distressing (placing an ethical duty on the researcher to terminate the interview and perhaps revisit the study design) (43,46).

Narrative interviewing and analysis are specialist skills that few health care researchers possess. Narrative research undertaken by untrained researchers is no more reliable than epidemiological research undertaken by those ignorant of basic statistics. Narrative research also involves a judicious trade-off between sample size and depth of analysis. Most qualitative interviews are semi-structured (i.e. the researcher goes through a list of prompt questions). A narrative interview (particularly when asking about a life story) should be conducted more like a conversation and be driven by the researcher's curiosity rather than using a predefined set of prompt questions (18,19). Such interviews tend to be lengthy and require extensive analysis. Correspondingly, sample sizes tend to be small (and hence, in a statistical sense, unrepresentative).

In summary, the limitations of narrative research are significant and should always be borne in mind. Stories should not be rejected entirely as a form of research evidence but individual narratives should never be used as proof of causality or as a direct, undistorted, window on people's experiences and perspectives.

2.1.5. How might narrative research be used in health policy and planning?

The growing popularity of narrative research in health care stems from "a desire to capture the local and textured character of experience against the simplifying abstractions of behaviorist theorizing" (47).

Abstraction, in this context, means converting phenomena to variables and expressing research findings as the relationships between these variables. Typically, researchers seek to determine the degree of correlation between receiving or not receiving an intervention or exposure (independent variable) and a quantitative



measure of disease severity and/or health-related quality of life (dependent variable). Such research has an important place and can produce valid and reliable estimates of the magnitude of a problem and the impact of specific interventions. However, as Ramiller and Pentland have observed, "When we enter the world of variables, we leave behind the ingredients that are needed to produce a story with the kind of substance and verisimilitude that can give a convincing basis for practical action" (48).

Arthur Kleinman distinguished narratives of disease (depicted as body or mind malfunctioning), narratives of illness (depicting the individual's subjective experience) and narratives of sickness (from the perspective of society) (9). Mike Bury offers a more sociological taxonomy of illness narratives (5):

- *contingent narratives* convey a person's beliefs about what caused an illness and how it is likely to unfold (what others have called lay epidemiology);
- *moral narratives* depict how illness alters identity and the individual's relationship to wider society; and
- *core narratives* reveal connections between the individual illness experience and deeper cultural meta-narratives.

In 2007, the WHO Regional Director for the Western Pacific, Dr Shigeru Omi, announced that, in a world where health systems are increasingly biomedical, provider oriented, bureaucratic, fragmented and alienating, we need to orient our efforts towards people-centred health care – that is, a system in which "individuals, families and communities are served by and are able to participate in trusted health systems that respond to their needs in humane and holistic ways" (49). People-centred health care is also a focus for the WHO European Region's policy Health 2020 (2).

Omi suggested four linked domains in which this people-centredness should be developed (49):

- individuals, families and communities, by improving health literacy, supporting self-care, strengthening lay support networks and offering the community a voice in local policy-making;
- health practitioners, by developing professionalism and a holistic approach to patient care;
- health care organizations, by promoting accessibility, patient-centred care pathways and responsiveness; and
- health systems, by a coordinated, intersectoral approach to such things as professional standards, accountability, workforce and so on.

These four interlinked domains offer opportunities for using narrative evidence productively in health policy.

At the individual level, narrative is increasingly used in health communication and education (50). Narratives, as rhetorical devices, are effective in persuasion (51,52), particularly if they capture cultural contexts (53). Health education in which the message is framed as a story can be more effective than when the message is given as so-called facts (54–56). One group of researchers has developed a narrative engagement framework for designing preventive interventions, based on the principles of rhetoric (57), although few public health practitioners are, as yet, trained to create or use such stories (50). Furthermore, the use of narratives (i.e. fictional vignettes written by experts) as simple communication devices in health education overlooks the pervasiveness of the moral and core narratives in Bury's taxonomy (5) and does little to address the underlying inequalities that may explain unhealthy lifestyle choices.

More radical uses of narrative methods include community-based participatory research, in which community members contribute actively to an enacted narrative, generating a dataset that informs the work of a community–campus partnership for health improvement (58); and participatory theatre for underserved groups oriented to raising awareness of, and collectively addressing, social and environmental barriers to health (59,60).

An early advocate for narrative methods in professional education was Patricia Benner, who used phenomenological philosophy to illustrate the link between narrative, empathy and caring in nurses (61). A comparable initiative in the education of doctors was pioneered by Rita Charon (6,62): in her words, "The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others" (6).

The use of narrative to inform and inspire the organization and delivery of health services was developed in the United Kingdom by Paul Bate and Glenn Robert (63). In an approach they called experience-based co-design, stories told by patients and their relatives (along with those told by staff) were used to identify emotionally significant touch points in the care pathway, thereby inspiring key improvements and motivating staff to implement these (63).

The macro-level narratives (discourses) in policy documents can be studied by asking questions such as "who are the key characters?", "what events and phenomena are



depicted as the 'trouble?', "what options are presented for resolving the 'trouble' and in what way is one option depicted as better than others?", thereby identifying the hidden, taken-for-granted assumptions underpinning policy decisions (24).

Public health projects and programmes can be thought of as nested in grand narratives that can be revealed by looking for metaphors and underlying storylines. Janine Talley, for example, has questioned the ubiquity of machine metaphors for the human body in health policy (comparable to a car; made up of systems and parts that can go wrong; requiring periodic servicing and fixing; and with nothing comparable to the mind or soul) (64). Such metaphors support the framing of human illness as fixable defects in single organs (Kleinman's narratives of disease (9)); they overlook that humans, like all living things, are flawed and subject to unavoidable entropic processes (but are also self-repairing), and they place limited emphasis on the importance of social and aesthetic influences on health and well-being (Kleinman's narratives of illness and sickness (9)).

The overarching policy and public health discourses within which particular interventions and programmes are nested are rarely obvious until they are pointed out and explored. Narrative analysis at macro-level can demonstrate the rhetorical nature of policy-making (65) and allow analysts to identify specific claims, which can then be either verified or refuted (66). Participatory narrative approaches can also be used formatively in the policy-making process, not least because they reveal alternative framings of issues (67,68).

2.2. Examples of narrative research on the cultural contexts of health

This section gives three examples of the use of narrative methods to enrich and extend other research methodologies in health-related areas. All the case studies are contemporary major challenges for public health and health policy relevant to the countries in Europe – and all have wider relevance internationally. Together, they illustrate how high-quality narrative research can:

- complement the findings of randomized trials and observational studies;
- inform new hypothesis-driven studies and refinement of survey instruments;
- explain the failures and partial successes of past policy initiatives; and
- inform the introduction and implementation of new policies.

2.2.1. Case study 1: cultural aspects of nutrition

There is a growing international crisis of obesity-related diseases, including diabetes, cancer, arthritis and stroke (69). A 2012 report entitled “Healthy agriculture, healthy nutrition, healthy people” recommended adjustment of fat and reduction in sugar content of foods (particularly fructose-containing soft drinks); universal access to a healthy diet as a human right; closer links between agricultural policy and health and nutrition policy; and research on gene–nutrient interaction in the onset and progression of noncommunicable diseases (70).

A 2015 report to the European Commission presented quantitative data on progress against five aspects of food- and diet-related policy across Member States: education (including lifestyle modification), advocacy and information exchange, composition of foods and availability of healthy food options, food labelling, and marketing and advertising (71).

Neither of these initiatives consider why people consume the foods they do and what food means to them. Effective initiatives also need an evidence base on these two aspects. Epidemiological studies have demonstrated wide variation in dietary patterns across European countries, with some groups also experiencing significant food insecurity (72,73).

Strategies to reduce the burden of obesity-related diseases include a cross-sector, multifaceted approach to food and nutrition. This, however, has to consider both the food available to people and the crucial importance of the social context in influencing dietary choices. Crotty, in considering the value of qualitative research in nutrition, stated, “The act of swallowing divides nutrition's 'two cultures', the post swallowing world of biology, physiology, biochemistry and pathology, and the pre-swallowing domain of behaviour, culture, society and experience” (74). It is the latter culture that can be accessed by narrative research. Narratives help in understanding people's dietary choices as embedded within cultural practices, in exploring the challenges faced when seeking to eat healthily in a more or less obesogenic environment and in considering the influence of factors such as material poverty, food insecurity and displacement.

A narrowly scientific approach overlooks the fact that the purchasing, preparation and consumption of food are social practices (i.e. recurrent shared activities made up of bodily actions, mental schemas, meaning systems and tacit know-how) that are deeply embedded in historical and cultural traditions (75,76). Changing these practices is difficult for individuals and communities. From the breaking of bread



in church to the McDonald's "happy meal", the communal consumption of food at particular times and in particular places has symbolic as well as nutritional value; such practices both reflect and reproduce the social order (77). It follows that diet is not a simple rational choice and that evidence-based dietary recommendations will not change behaviour if provided in a cultural vacuum.

Halkier and Jensen, for example, used photo-elicitation (inviting participants to take a photograph of their meal and then tell a story about it) and narrative interviews to study the food practices of Pakistani families in Denmark (78). The study was in the context of rising prevalence of type 2 diabetes mellitus in Danish south Asian groups and official advice to these groups to adopt a more Danish diet based on rye bread and dairy products. The authors sought to explore "how food is embedded in the multiple social relations and conditions of everyday life", and in particular to identify what was acceptable and expected healthy eating in the families and community studied. They identified four contrasting practices, which they present as so-called ideal types (to which individual participants conformed to a greater or lesser extent) (78):

- engaging proactively in healthier food, which involved consciously and consistently exchanging traditional food ingredients and cooking methods for ones perceived as more healthy;
- fitting in healthier food by making some healthy compromises in the privacy of the home but prioritizing cultural traditions and expectations in social settings;
- doing healthier food ambivalently and so talking about eating healthily but actually making multiple compromises (e.g. convenience and street food to accommodate a busy schedule); and
- ignoring healthier food for social practicality and prioritizing other aspects of food such as meeting the desires and expectations of family members, sometimes in ways that play out gender and age expectations (e.g. a grandmother expecting to cook a favourite dish to please a young adult grandson).

Their findings revealed that Pakistanis in Denmark do not consume unhealthy food out of ignorance. Rather, they engage actively in balancing recommended healthy food practices with other cultural practices and behaviours and with the practicalities of life and work schedules. The conclusions drawn from the study are important: public health policies should shift from an approach based on a deficit model (which seeks to redress assumed deficiencies in knowledge, motivation, resources and so on) to one based on encouraging healthier food in social practices and making healthier convenience food options more widely available.

Social practice was also examined in the context of people's attempts to follow a cholesterol-lowering diet in the United Kingdom (79). In narrative interviews with 89 participants aged 24–90 years, four different (and potentially conflicting) repertoires that drove people's dietary practices were identified: health, pleasure, sociality and pragmatism. Most participants talked in general terms about healthy eating (e.g. "I have salads") but that when asked to describe what they actually ate the previous day, they described much less healthy food (e.g. "bacon and sausage on toast"). A noteworthy finding was that healthy – and unhealthy – eating appeared to happen in particular locations and particular social situations. For example, one man described how his food choices at home were determined by his wife, who strove to provide the family with a healthy diet, whereas he felt he could choose freely in the work canteen, by which he meant driven by his own appetite and the cultural norms and expectations of his peer group. Again, this study illustrates the limitations of the deficit model and the need to consider the social settings in which food choices are made.

Similar findings on the crucial importance of social context in influencing dietary choices were obtained from a focus group study of Dutch, Moroccan and Turkish participants in the Netherlands (80) and from a photo-elicitation study in the United Kingdom (81). Both studies highlighted techniques of neutralization in which participants emphasized how they succeeded in avoiding one unhealthy behaviour (e.g. smoking) when they described making an unhealthy dietary choice.

Food beliefs and ethnic practices can also influence dietary choices. A study of Bangladeshis with diabetes in London used narrative interviews and ethnographic observation of meals (82). They found that foods were not classified or selected according to western notions of food values (protein, carbohydrate, etc.). Rather, food choices were determined primarily by religious restrictions and ethnic customs and secondarily by two linked binary classification systems: strong/weak and digestible/indigestible. Strong foods (such as egg yolk or ghee) were considered necessary and health giving for certain groups and states (e.g. growing children, pregnant women and convalescents); weak ones (such as overboiled rice) were for the sick and debilitated. Indigestible foods (considered a poor choice for anyone) included raw food and anything that grows below the ground (including potatoes, a food commonly recommended by dietitians). As for the Pakistani families in Denmark described above (78), these south Asian participants found the advice from professional dietitians meaningless (and hence impossible to follow).

Recent developments in narrative research on diet have focused predominantly on stories told in a real-world setting (online blogs and the influences of commercial



interests) rather than those collected specifically for research. Compared with universal, population-based accounts of healthy eating told by public health experts (based almost exclusively on epidemiological knowledge), nutritional bloggers construct more individualist narratives. For example, Huovila and Saikkonen in Finland have studied the (inconsistent and conflicting) narratives about diet and food shared in online communities through blogs (83). Nutritional bloggers emphasize "practical, subjective and moral knowledge" – that is, the knowledge of one's own body and the practical and moral judgements needed when negotiating food choices in social situations. The authors proposed that debates about healthy eating in the public domain are essentially an epistemic struggle (about what kind of knowledge is important).

Another emerging stream of narrative research in this field is the macro-discourses in society about food. One such discourse depicts diet and nutrition as a multibillion dollar industry (big food) with large international corporations controlling the entire pipeline from the production of food (often in distant countries) to the consumer's plate (84). Discourse analysis has also revealed the power of metaphor in influencing how beliefs about the causes of obesity (as slothful behaviour, as addiction, as eating disorder, as the consequence of manipulation by commercial interests and so on) affect support for public policy (85), and how concepts of food security and food poverty are (in the view of the researchers) strongly influenced by neoliberal notions of consumerism (86).

2.2.2. Case study 2: the cultural context of well-being

The WHO's constitution defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (87). Health 2020, the WHO European Region's health policy framework, takes a multisectoral approach to improving health and well-being and reducing inequalities (2). In this framework, good health is seen as an asset and a source of economic and social stability; poor health can often be explained by social determinants such as poverty, education, housing, employment and so on. There is growing recognition both within and beyond WHO of the need to take account of a broader conception of development than a country's gross domestic product, and in particular to include measures of well-being (88–90).

The question of how to measure well-being is contested (91). Some argue that well-being is an inherently subjective phenomenon, measurable via such things as life evaluations (a reflective assessment on life or some aspect of it), affect (a person's feelings or emotional states) or *eudaimonia* (achieving meaning and

self-actualization) (92–94). There are ongoing debates, beyond the scope of this report, on whether well-being is a universal trait (hence, comparisons across diverse settings are legitimate) or a culturally specific one (hence, such comparisons are inherently problematic) (95–97), and on whether the focus on individual well-being diverts us from a more critical analysis of the structural inequalities in society (98).

WHO seeks to supplement quantitative indices of subjective well-being with both objective measures of external (and potentially modifiable) influences such as employment, housing and social connections and narrative evidence of the nature of the well-being experience (99). The latter could play an important role in bringing quantitative metrics to life, exploring and contrasting the diverse cultural contexts in which these metrics play out, and helping to theorize the individual experience of good or poor well-being (97). However, this topic has not yet been widely researched using narrative methods.

Narrative adds granularity to survey data. For example, a narrative study of precarious prosperity described a middle-aged, college-educated Swiss woman whose monthly income was above the national average (100). Her income came from a series of unfulfilling, short-term jobs, for which she had to travel and live in temporary housing. The jobs offered little or no employment rights and did not make use of her professional qualifications or experience. The authors comment that this was paradigmatic of "the population situated just above the poverty threshold, struggling to avoid slipping into poverty while facing real threats of downward mobility".

Two books have collated narrative case studies on well-being from different countries: "Pursuits of happiness: well-being in anthropological perspective" (2008) (101) and "Cultures of well-being: method, place, policy" (2016) (95). Significantly, neither includes examples from Europe, confirming the dearth of this kind of research in European countries. Selected contributions from those books are described below.

Laura Camfield considered how qualitative (including narrative) data could contribute to the development and refinement of survey questions about well-being (102). Summarizing research by others, she considered the measurement of child poverty in rural Ethiopia. As part of scale development, three rounds of qualitative data collection were undertaken from both children and adults, including open-ended questions about how different levels of poverty would be classified in this society. Findings indicated that poverty was not merely about the material and economic value of property and possessions (including ownership of land and animals) but also about the symbolic and relational value of these in Ethiopian society.



A simple material indicator, such as ownership of oxen for example, had high cultural significance in the qualitative data ("if an individual buys a pair of oxen then he is considered ... equal to others since he is able to farm [his] own land independently"). Similarly, ownership of particular items of clothing was viewed as reflecting self-esteem and social participation ("they are well clothed and hence are proud to mix with the community in places where the community meets").

Emer Brangan used narrative (including ethnographic) methods to supplement quantitative measures of well-being in a South African township with a high and rising prevalence of type 2 diabetes (103). The study was inspired by Brangan's concern that:

the discourse around public health policy on prevention was "expert" driven; the vast majority of the research on which policy was based was quantitative and had been carried out in high-income countries; and the "public" were often cast as a group to be manipulated in order to change their behaviour, rather than as stakeholders with knowledge, values and reasons which warranted respectful attention.

Brangan described a narrative interview with Nombeko, a 55-year-old woman with multiple co-morbidities (including a past stroke), who, a few months previously, had ticked the boxes "difficulty walking" and "uses cane or walker" on a general health survey. He reported conversation verbatim:

Nombeko: Even now you saw me sweating, walking very fast; I cannot walk slowly, I have to walk fast.

Interviewer: Really, so do you see yourself as an active person?

Nombeko: Yes because I love exercising; I am able to walk from here, Langa, and go to Belville [approximately 8 miles/13 kilometres].

Interviewer: You walk to Belville!

In this extract, Nombeko conveys not merely that she can and does walk but that she loves walking. Elsewhere in the narrative interview, she describes how she left school before completing her secondary education but has now returned to college with a view to obtaining a qualification in community work; she says that she is highly motivated to exercise as part of the rehabilitation from her recent stroke. Brangan discusses the mismatch in the data (why did Nombeko tick the box "difficulty walking" and claim to need a walking aid?): perhaps her difficulties had been temporary (people may recover from stroke); perhaps the other questions asked in the survey (about disability) had coloured Nombeko's self-perception; perhaps she did indeed perceive difficulty walking but not sufficiently to stop her walking

8 miles; and so on. Whatever the reasons, the survey instrument conveyed a (vague and abstracted) picture of a woman with disabling multimorbidity whose quality of life was likely to be low, but the narrative interview depicted an active, ambitious woman whose multiple illnesses were not stopping her from pursuing her goals.

Davies used narrative interviews and photo-elicitation to explore the impact of landmine clearance on well-being in a Cambodian village (104). Many narratives described past psychological stress resulting from uncleared landmines, including severe restrictions on movement, reduced social interaction, inability to take crops to market and children unable to attend school. Most photographs taken were of the land; elicited narratives emphasized the critical importance of working the land to stay out of poverty. Before the landmine clearance programme, said one participant, she and her husband could only farm the land up to 5 metres from their house; afterwards, land access had increased substantially and economic hardship had eased. Another participant put it more bluntly, "landmines make us poor".

Narrative research on well-being raises philosophical questions about what well-being is. Bauer and colleagues have argued that eudaimonic well-being has a narrative dimension, reflecting the ongoing construction of identity in context and linking to Aristotelian notions of the good life (virtuous, restrained, meaningful) (105). Hayward and Taylor challenged dominant biomedical models of rehabilitation after illness or trauma, emphasizing not merely the recovery of muscle power or functional skill but the ability to engage meaningfully in society and gain fulfilment by contributing to it (106). At this level of abstraction, well-being is perhaps the same construct in all cultures – but the more concrete answer to what is meaningful and what is fulfilling will vary (and must be explored).

More commonalities than differences were found in the well-being narratives of older people from both white British and immigrant groups in the United Kingdom. In the context of a project examining use of assistive technologies for healthy living for elderly people, ethnography, narrative interviews and photo-elicitation were carried out to assess 40 older people with multiple health and social care needs (107). Of the 40 participants, 20 agreed for their case narrative to be reproduced on the study website (<http://www.atheneproject.org/Case%20Studies.html>). A key finding was that chronic illness prevented people from doing the things that mattered to them and that gave them meaning and identity. While the specifics of what mattered were culturally framed, the feelings of loss and hopelessness at losing the connection to what mattered were common across the cultural groups studied, and so-called assisted living technologies rarely restored this connection.



This study and similar work in the Netherlands (108) and Spain (109) highlight the limitations of the biomedical model of tele-health and tele-care (which focuses on how technology can support monitoring, surveillance and the pursuit of safety, arguably at the expense of the well-being of its intended user). As Sayer has observed, "A key characteristic of pain and suffering is that they are not merely states of being, but of frustrated becoming, or continuous yearning for relief and escape" (110).

An additional source of narrative evidence on well-being could be historical archives or the cultural record more generally (e.g. novels, plays or blogs); while such sources are often plentiful, this report could identify no published evidence on how they might be used to enrich the measurement of well-being in the cultural context.

2.2.3. Case study 3: mental health in refugees and asylum seekers

Most health-related research on refugees and asylum seekers focuses on demographic trends and quantitative measures of health status, needs and provision. A key concern in this literature is consistency of definitions and categories in order to make cross-national comparisons and longitudinal follow-up studies meaningful (e.g. what is an asylum seeker (discussed in other Health Evidence Network reports), what is poverty or what is a mental health disorder). Such research is important and much progress has been made in recent years. Narrative research can provide an important complement to deterministic, variables-centred research and the bureaucratic need for standardized categories (43).

A number of factors may affect mental health in migrants, including the effect of forced migration and disruption, trauma and psychological stress, issues of acculturation, and interaction with the asylum system and the health care system. Ruiz and Bhugra proposed a taxonomy of variables that impact either positively or negatively on the acculturation process for migrants (i.e. integration, assimilation, rejection or marginalization), including sociodemographic variables (e.g. age, sex, marital status, ethnicity and religion), societal variables (e.g. extent to which the host society is pluralist, tolerant, racist and so on), migrant group variables (e.g. whether temporary workers, sojourners, immigrants, asylum seekers or refugees), sociological and psychological variables (e.g. coping styles and previous experiences such as maternal deprivation, degree of powerlessness and level of rigidity) and behavioural variables (e.g. accidents, drugs/alcohol and crime) (111). They comment, "These variables, as well as the final mode of resolution of the acculturation process, will determine the final degree of positive or negative outcomes when resolving the impact of the acculturative stress".

A major factor that can lead to mental health issues for migrants is trauma related either to events in their home country that precipitated their migration or to the journey itself. In 2011, the European Observatory on Health Systems and Policies described and quantified patterns of voluntary and forced migration into and within the countries of Europe and their effect on health (112). One section of that book highlighted the higher prevalence of both nonspecific psychological stress and psychopathology (e.g. medical diagnoses such as depression, anxiety, post-traumatic stress disorder and schizophrenia) in forced migrants than in the general population or voluntary migrants (113). The preferred explanation is the life-course violence model: traumatic events taking place before and during migration may have latent effects, leading to vulnerability to illness that can be triggered at later times, and particularly when exposed to adverse circumstances following migration. The authors described a dose–response relationship between the violence experienced and the level of psychopathology and that is moderated in some individuals by a healthy migrant effect (people who are more resilient are more likely to migrate) (113).

In the field of forced migration, Marita Eastmond has argued that a narrative approach allows exploration of "how people themselves, as 'experiencing subjects', make sense of violence and turbulent change" and to appreciate the diversity of experience "against universalizing and stereotypical descriptions of what it means to be a 'refugee'" (43).

Narrative research is perhaps uniquely important in this complex field of enquiry since forced migrants have experienced – and often continue to experience – a profound form of biographical disruption ("Refugees are in the midst of the story they are telling, and uncertainty and liminality, rather than progression and conclusion, are the order of the day" (43)). Narrative is needed both to make sense of past traumatic experience and to seek ways of going forward (often couched within the meta-narrative of a wider religious and/or political diaspora).

A study based more explicitly on narrative theory involved in-depth biographical interviews with a sample of just four young men living in Norway and originally from north Africa, the Middle East or south Asia (114). All had been victims of forced migration several years previously as teenagers and had subsequently become dependent on opioids and made suicide attempts. The analysis used a phenomenological approach (i.e. focusing on the subjective perceptions and interpretations of the narrator). All four accounts conveyed a strong sense of risk and danger in the emigration process, followed by confusion, isolation, insecurity



and hopelessness after arrival in Norway ("living in a maze"). This occurred in parallel with the difficult transition from adolescence to adulthood. The men described ongoing tensions and repeated conflicts in Norwegian society – particularly between fear of being rejected by new acquaintances on the one hand and a feeling of moral duty to defend their culture and country of origin on the other. Both substance abuse and suicide were framed in the narratives as the only means of escape from this intolerable situation. Having conveyed the complexity of these experiences in detail, and (as far as possible) from the perspective of the young men, the authors expressed hope that their study would help to improve the sensitivity of health and social care professionals as well as to inform policies that enhance a sense of security, belonging and identity performance in immigrants and reduce potential external conflicts between immigrants and the indigenous population (114). Perhaps, in addition, the emotionally appealing narratives conveyed in this research help to make sense of the troubling social phenomenon of young immigrant men descending into drug abuse and self-harm and to provide a convincing basis for practical action (48).

Two clinical case studies are described below that can be considered as narrative research in the sense that the authors use story interpreting in order to develop theory (see section 2.1.2) but they are both one step removed from the actual voice of the displaced individuals in that it is the researcher's voice that is heard. The collection and interpretation of narratives from victims of oppression, torture or political violence raises profound challenges for researchers, since "in the violation of individuals' bodies and minds, traumatic experiences fragment memory, undermine trust, and inhibit expression" (43). Studies of this type raise questions about the extent to which a person's doctor or therapist is able to advocate for the individual in academic texts (and the legitimacy of their moral mandate to do so).

The first clinical case study, by academic psychiatrist Derek Summerfield, is a narrative describing an in-depth analysis of a 32-year-old Hutu Rwandan refugee, with the pseudonym of Sara, seen in a psychiatric referral clinic in the United Kingdom (115). He described her background (she saw her parents murdered in front of her before she was kidnapped, imprisoned, mutilated and repeatedly raped by Tutsi soldiers; she escaped with the help of a priest and had not heard anything of her husband or five children since). He also described an awkward clinical encounter in which Sara refused to continue the consultation until the Tutsi interpreter had left the room. She insisted that she was "not depressed, but ill". She described cramped living conditions, thieving and conflict in the hostel where she was staying; she attributed her headaches and lack of energy to this, along

with her past traumas. The psychiatrist ascertained that Sara was not suicidal and did not arrange to see her again. His reflective commentary addresses whether and to what extent western psychiatry, with its biomedical disease taxonomy and pharmacologically focused therapeutic menu, is an appropriate service for Sara and others like her. While his chapter rests on a single, richly described case narrative, it raises important questions about the suitability of this service model for people such as Sara.

The second clinical case study, by academic psychiatrist Roberto Beneduce, offered an in-depth analysis of six narratives of forced migrants from Africa to Italy, all of whom had been diagnosed with formal psychiatric disorders (116). These detailed and troubling narratives were presented as core narratives, as described by Bury (5) (see section 2.1.5), nested explicitly in historical-cultural meta-narratives of oppression and discrimination. Beneduce expressed concern that one unintended consequence of the psychiatric assessment is that these meta-narratives become obscured by the medical diagnosis (116).

While migrants' symptoms often bear cultural hallmarks of suffering, they also reveal images of a traumatic history, which resurface in moments of danger, uncertainty, and crisis. [These, suggests Beneduce] are allegories of a dispossessed past, and can be interpreted as counter-memories, as "palimpsests" of an eclipsed script. Trauma symptoms keep returning to a collective past, and thus can be considered a particular form of historical consciousness. Psychiatric diagnoses may obscure these counter-memories. In particular, the diagnostic category of posttraumatic stress disorder that is commonly attached to traumatic experiences in current clinical practice recognizes the truth of individual traumatic events, but at the same time contributes to concealing the political, racial, and historical roots of suffering.

Partly because of the difficulty in obtaining authentic, first-person narratives in this field of enquiry, some authors have used a more radical, semi-fictional approach to conveying sufferers' experiences. Dr Joseph Achotegui, Professor of Psychopathology at the University of Barcelona, has described a new syndrome, Ulysses syndrome, which he defines as a combination of both physical symptoms (e.g. insomnia, headaches and tiredness) and psychological ones (e.g. hallucinations, irritability and anxiety) experienced by migrants facing multiple stressors (117). This is not an accepted mental health disorder under the WHO "Classification of mental and behavioural disorders" (118), as post-traumatic stress disorder is, for example. Rather, Achotegui suggests that it is an extreme form of migratory mourning, a holistic disorder of well-being generated by the extremes of context and hence



is better studied with reference to myth and meta-narrative than to medicine's manuals of diseases (117). It is named after Homer's Greek hero Odysseus (known as Ulysses in Roman myths) who spent 10 years through a long and exceptionally harrowing sea journey to return to his home after the fall of Troy; far from his loved ones, he spent days "sitting on the rocks, at the edge of the sea, setting eyes on the barren sea, crying inconsolably" (119). The syndrome has been described (120) in the following way:

The Ulysses Syndrome takes place at the extreme level of stressors. The complex migration context may include factors causing high levels of stress such as: forced separation, dangers of the migratory journey, social isolation, absence of opportunities, sense of failure of the migratory goals, drop in social status, extreme struggle for survival, and discriminatory attitudes in the receiving country.

Rather than explaining the symptoms of Ulysses syndrome in terms of combinations of variables (people migrate, not theoretical constructs), Achotegui instead draws parallels with the intercultural story of Ulysses, whose identity is so profoundly damaged from his ordeal that he says, "You ask me my name. I shall tell you. My name is nobody and nobody is what everyone calls me" (119).

Achotegui draws extensively on numerical data to describe the problem of forced migration but he also provides detailed case narratives of individual migrants and makes explicit and rhetorical use of metaphor. For example, he acknowledged that most immigrants do not arrive by raft but viewed the raft (precarious, makeshift, risky) as the perfect metaphor for the migration journey. He quoted his patients' use of metaphor (one said, of his sense of confusion, "it is as if I had a centrifuge in my head, working all day"). He used his own metaphors and imagery to illustrate the near-unbearable tension between hope and despair experienced by many forced migrants (117):

Broken dreams; this is the land where dreams die. The worst shipwreck is on land, when, after so much effort, one cannot get ahead. They bring a backpack, a suitcase with a few belongings, but full to the brim of illusions. What is most bulky are their dreams ... dreams of a better life.

Achotegui emphasizes the fact that most forced migration journeys today are undertaken alone rather than as a three-generation family as described by John Steinbeck in "The grapes of wrath" (121); his fictional Joad family were forced to migrate by severe economic hardship but did so as a supportive unit. The rhetorical devices of association (with the lone Ulysses, who "goes with a heavy heart and

his mind fixed on his valiant father" (119)) and dissociation (with the Joad family unit (121)) combine to make a powerful narrative point about existential isolation.

As discussed, migrants can face mental health issues not only because of their reason to migrate but also from their migration journey. However, once they reach a final, or near-final, destination, then they also face post-migration issues. Narrative studies have made an important contribution to illuminating the detail of what migrants have gone (and are going) through, what Bury called the contingent narrative (5). Such research suggests that the host country is typically experienced as hostile and as compounding traumas already experienced. Robin Wilson from the Refugee Action Group, for example, provides eight detailed (anonymized) narratives of asylum seekers from sub-Saharan Africa and Asia (122). All had been placed in detention in Northern Ireland prior to deportation after a failed asylum application. The narratives powerfully illustrate a number of common themes: the prevailing culture of suspicion, the severe emotional and physical effects of detention on the individual, the traumatic nature of how people came to be arrested and detained in the United Kingdom, the ubiquitous sense of confusion and not-knowing, and the details of the abject conditions in many detention centres.

Bernardes et al. conducted a mixed-methods study in the United Kingdom of 29 asylum seekers from 13 countries of origin using a mental health screening questionnaire to provide a descriptive overview of participants' symptomatology (123). Qualitative interviews in a subsample provided insights into what these symptoms meant to participants and what they attributed them to. The authors concluded that "psychological distress is common among asylum seekers (for example anxiety and post-traumatic stress), but so are post-migratory living difficulties (for example accommodation, discrimination, worry about family back home, not being allowed to work)".

A number of narrative research studies of forced migrants have focused on their experiences of the asylum system – a significant source of stress (122,124,125). The 1951 Geneva Convention offers protection (asylum) for those who are in "fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion" (126). All asylum systems have formal eligibility rules, but they also have informal, culturally shaped assumptions about what counts as a credible and deserving asylum seeker. Asylum seekers must learn both sets of rules and play by them – both when making their initial claim and in appealing against the (usually negative) first decision.



Jane Herlihy and colleagues reviewed the psychological literature on autobiographical memory in relation to asylum seekers (125). Their findings challenge the assumption that people can reliably, consistently and accurately recall autobiographical memories, particularly in relation to distressing events and when the individual has been displaced from homeland and social networks. Post-traumatic stress disorder is known to distort memory (perhaps as a protective or adaptive response), and talking therapies will prompt re-tellings that differ from earlier version. While specific, detailed memories are viewed by the legal system as more credible, people with depression and/or traumatic pasts tend to produce memories that are vague and lacking in detail. The difficulty of telling and making oneself understood across widely divergent cultures (especially when the narrator is relatively inarticulate regardless of language) is sometimes prohibitive. In addition, since so much is at stake, the pressure to embellish or fabricate is high. For all these reasons, a coherent, consistent account of persecution is unlikely, particularly in the most traumatized.

In a paper entitled "The moral economy of lying", Roberto Beneduce analysed the narrative strategies used by immigrants to meet the eligibility criteria established by Italian asylum law (124). Putting together a case for asylum is a complex act of bricolage before a system that exhibits what Beneduce calls bureaucratic violence: "When the search for suffering and violence is reduced to a mere collection of causes, circumstances, and evidence, those who cannot produce documentation inevitably become suspect in the eyes of those questioning them". The paper is illustrated with real clinical vignettes describing how some asylum seekers learn to adjust their story to achieve the kind of narrative (accompanied by documentation or plausible physical scars) that is likely to have maximal rhetorical power in the system.

Yet, as Beneduce pointed out, accounts by forced migrants exhibit a form of narrative truth, since the dysnarrated stories (either deliberately or subconsciously distorted) often convey genuine underlying plotlines of risk, danger, exploitation, physical or sexual violence, social exclusion and discrimination (124). Eastmond posed the intriguing suggestion that, in asylum applications in which the victim's own narrative is unforthcoming or untrustworthy, the responsibility for constructing a credible narrative increasingly falls to the medical examiner: "As the injured body has become the terrain of 'truth', medical certificates are replacing refugees' own words" (43).

One area in which narratives of forced migrants have been researched successfully is in the study of experiences of the health care system. Two studies asked about

such experiences, one through narrative interviews with 20 Somali refugees in Sweden (127) and one with focus groups with 34 Somali refugees in the United Kingdom (128). Findings were similar (and in agreement with those of Bernardes et al., described above (123)): a high regard for the health care system in the host country (and high expectations of it), but difficulty accessing services (particularly when moving between temporary housing) plus perceptions of discrimination from health care staff. Participants felt that their problems and culture were not well understood by health professionals, who (allegedly) did not take them seriously. In the United Kingdom study (128), high use of accident and emergency departments was attributed by Somali refugees to being refused care (or their concerns being dismissed) by general practitioners. These studies have direct and important lessons for the redesign of services and the education of staff.



3. DISCUSSION

3.1. Strengths and limitations of the review

This review has three main strengths. First, the methodological approach to summarizing and synthesizing evidence (hermeneutic review) was shown to be appropriate to the subject matter (narrative research has strong links to the humanities and it would have been inappropriate to apply the traditional hierarchy of evidence). Second, the report has taken a "show rather than tell" approach, illustrating with a wide range of real examples how high-quality narrative research can complement and extend traditional approaches. Third, earlier drafts of this report were extensively revised following editorial and peer review, thus allowing the interpretive responses of other scholars to serve as a driver of quality.

The main limitations are twofold. First, because the inclusion of narrative research is a relatively new approach in health reporting and has happened predominantly in America, Africa and Asia, many of the examples are not from Europe. Second, the traditional short and accessible format of these reports has meant that detailed discussion of theory and empirical examples was not possible.

3.2. Summary of findings

This report, commissioned by WHO Regional Office for Europe on the advice of its expert group on the cultural contexts of health, sought to introduce narrative research and explore its link to culture. Individuals' stories of illness and well-being are a critical window to their meaning systems and values and are nested within wider narratives of society and culture.

A wide range of narrative research methods may be used eclectically and in combination to capture cultural contexts. These methods include the traditional clinical case study (particularly when closely analysed from a scholarly perspective), sociological studies of illness narratives (usually captured through narrative interviews), more contemporary sociological studies of the multivocal narratives of online communities (by narrative analysis of website text), anthropologically informed studies of cultural practices (using techniques such as ethnography and photo-elicitation), construction of organizational or community case studies, and the study of the meta-narratives that frame policy (using critical discourse analysis).

Key quality criteria for narrative research regardless of the technique used include measures to assure trustworthiness, plausibility and criticality.

One important caveat is that, because we are all familiar with stories and no special equipment is needed to collect or analyse them, the naive researcher or policy-maker may wrongly assume that no special expertise is needed either, and that the narrative elements of a health report can be put together simply by finding pretty quotes. The indiscriminate use of narrative methods by untrained (but well-meaning) researchers – particularly those whose background lies in empirical science rather than the qualitative social sciences or humanities – could weaken rather than strengthen health reporting and threaten the credibility of this method. It is, therefore, essential that the expansion of the methodological repertoire to include the use of narrative methods is accompanied by systematic attention to training and support in the relevant paradigm. Those seeking to use narrative to capture cultural contexts may need a basic grounding in the philosophical assumptions behind interpretivist social science as well as methodological training on how to undertake narrative interviews, ethnography, photo-elicitation and textual analysis.

While stories are evocative, memorable and can inspire the moral imagination, they are not true in any direct sense and are always open to multiple interpretations. The three case studies illustrate both the power of narrative to enrich traditional reporting and the potential for misinterpretation and distortion if particular narratives are given too much weight.

The studies on the influence of social factors on diet and nutrition (Case study 1) outline processes that have important implications for health education: unless educational messages also address the world of social practice and the wider discourses shaping our perspectives, for example on food and eating, they are likely to be ineffective. In addition, the narrative form may be a powerful tool for education on health issues such as diet, since cultural contexts could be incorporated to illustrate the practical and social challenges of particular food choices.

The shift in definition of health from absence of disease to a holistic, philosophically informed notion of well-being has inspired important work on how to measure this state. Narrative research on well-being, although currently sparse (particularly in a European context), offers great potential for exploring the cultural nuances of quantitative well-being metrics, refining those metrics and informing the debate on how and to what extent well-being can meaningfully be compared across cultures. Case study 2 indicated an unmet need for research on how assistive technologies



might be designed and implemented to support positive well-being rather than (or, perhaps, in addition to) simply monitoring biomarkers.

Research into mental health and well-being in refugees and asylum seekers is a complex and contested field, as Case study 3 shows. The evidence reviewed in this report suggests that quantitative data on who migrates, where and for what stated reasons, and on the prevalence of formal psychiatric diagnoses, can and must be supplemented by narrative studies of migrants' own experiences. However, collecting and analysing these narratives raises both methodological challenges (sampling, study design and interpretation) and ethical ones (the requirement to do no harm) for which there are no simple solutions.

At the individual level, narrative is increasingly used in health communication and education and can be effective in persuasion, particularly if it captures cultural contexts. Health education in which the message is framed as a story may be more effective than when it is given as just facts. Narrative approaches, used judiciously, offer potential to improve health at the level of the individual (by informing educational programmes), the community (by informing participatory research), the health professional (by promoting reflexivity and an understanding of the patient's perspective), the health care organization (by informing patient-centred redesign) and the health care system (by promoting a richer understanding of what policies are in place and how to influence them).

3.3. Policy considerations

This report supports an important shift in the approach to collecting and reporting the evidence base on the health status of both individuals and populations. The use of narrative research alongside more traditional methodologies will enable WHO and other organizations to shift from a narrowly biomedical and epidemiological approach to a more values-based approach that is better able to incorporate (and respond appropriately to) diverse cultural contexts.

It is suggested that:

- WHO should consider the judicious inclusion of narrative research in health reporting, particularly when cross-country comparisons are undertaken and/or a health or health care issue is strongly influenced by cultural contexts;
- policy-makers in Member States could consider how narrative research might support the design and evaluation of particular policies and interventions;

- academics should continue to develop the methodology of narrative health research and further explore how narrative evidence can be combined with more traditional measures of population health status; and
- specific studies to test the application of narrative principles to influencing health practices could use dietary practices as a fruitful area as currently such studies are sparse and diet and nutrition are priority areas for health status.



4. CONCLUSIONS

While the review makes no claim to be an encyclopaedic coverage of either narrative research in general or of the three case study areas in particular, the methodology appears to have been successful in supporting the preparation of a report that can promote understanding of the contribution that narrative could make to the more conventional forms of health information and evidence in illuminating the cultural contexts of health.

The expansion of the methodological repertoire to include the use of narrative methods must be accompanied by systematic attention to training and support in the relevant paradigm. Whatever the specific technique used, key quality criteria for narrative research include measures to assure trustworthiness, plausibility and criticality.

Used appropriately, narrative methods offer the potential to both challenge and enrich health reports and to inform the design and implementation of culturally congruent interventions.

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ANNEX 1. SEARCH STRATEGY

Methodological approach

The purpose of this report was to justify (where appropriate) the use of narrative approaches in different areas of health care policy-making, summarizing their strengths and limitations, and to provide illustrative examples with relevance for policy-makers. There was not a well-defined corpus of literature that addressed either the methodology or empirical examples in this field. Many key terms, such as narrative, culture and policy(-making), were very broad, making formal searches a challenge, and it was rightly anticipated that relevant examples would be spread widely across different literatures (academic and grey).

For all these reasons, the review task was not a simple technical one of developing a search strategy, running it in a range of databases, applying data extraction tools, producing summary tables and allowing the conclusions to fall out of the data. Indeed, it was clear from the outset that an overly technocratic approach, while superficially rigorous, could overshadow the crucial process of interpretation and judgement. Accordingly, three main principles guided the selection of review methodology: (i) it must be centrally concerned with *making sense* of a complex literature, (ii) it must allow for *iteration* and *progressive focusing*, and (iii) it must enable a flexible trade-off between *comprehensiveness* (of the search phase) and *intellectual depth* (of the interpretation phase). A fourth, more philosophical, principle was that since narrative is a fundamentally constructivist approach (i.e. it is based on the philosophical assumption that what is important is a person's – or a community's – construction of reality) the chosen methodology should be *resonant with constructivist philosophy*.

Guided by these principles, an approach – hermeneutic review – was chosen (see Annex 2).

Strategy

The author identified sources by beginning with a small selection of books and papers widely recognized as seminal in the field and then used various techniques (e.g. citation tracking or searching references of references) to expand from these while applying progressive focusing to limit the dataset.

Case studies were selected to illustrate the range of narrative approaches and how these can complement other data. Citation pearl searching (i.e. pursuing references of references and tracking books and papers in Google Scholar; see Annex 2) was used and continued until new sources contained no substantive new themes. Data extraction followed an interpretive rather than technical approach, with the goal of producing a rich understanding of each topic. Data were combined and summarized using narrative synthesis, following the standard structure for these reports.

The case study on nutrition began with the author's own work on dietary practices and from personal academic contacts, who suggested additional material and further contacts. When the key theme of eating as social practice emerged as central to this case study, a targeted search of medical and social science databases for this topic was undertaken.

The case study on well-being began by correspondence with members of WHO Europe's working groups and the grey literature reports they had produced. In this case, the author was initially unfamiliar with the field so posed an exploratory question on social media (Twitter) and carried out a fuzzy logic search of Google Scholar (trying different search terms and pursuing potentially promising links); these approaches provided links to new qualitative research sources including two edited volumes of narrative research on cultural contexts of well-being.

The third case study, on mental health in refugees and asylum seekers, began with an exploratory search of Medline and Google Scholar. These searches identified two scholars in the field who were known personally to the author; they provided both an overview of the field and the names of additional authors who had undertaken specifically narrative studies in this field.



ANNEX 2. HERMENEUTIC REVIEW

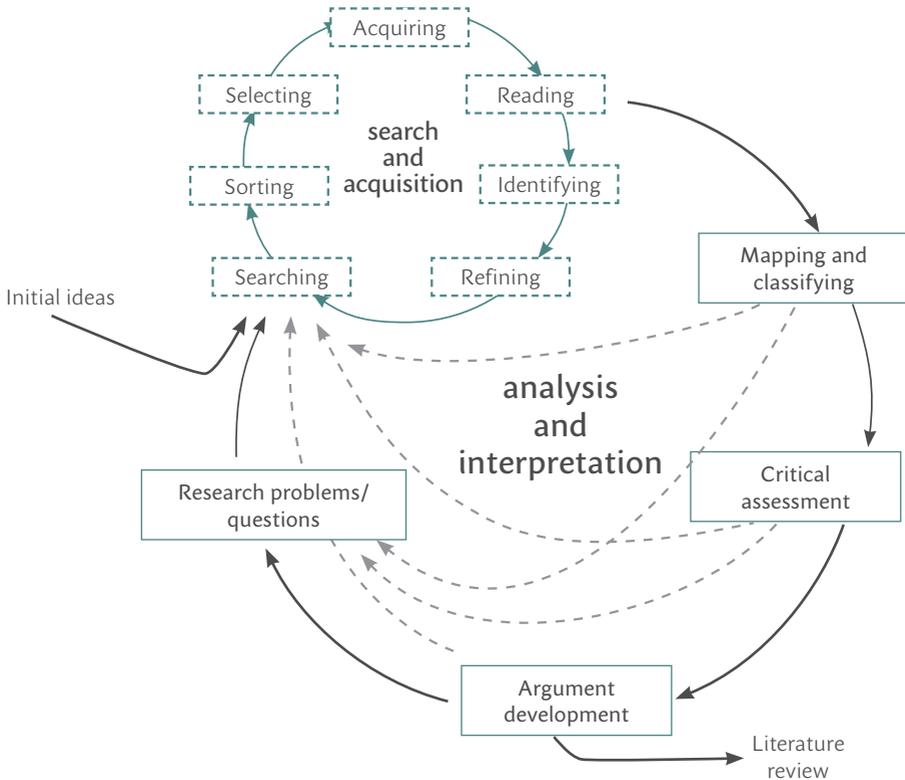
Hermeneutic review was developed in the field of information systems (which, like health care, has witnessed a huge expansion in research publications in recent years and struggles in particular with reviews of ill-defined, interdisciplinary and applied topic areas) (1). It is based on hermeneutic philosophy – a theory of interpretation that deals with the questions and meanings of texts. The goal of hermeneutic review is to achieve a better understanding of a field. While perfect understanding will never be achieved, understanding will progressively improve with close intellectual engagement with key texts. The method developed separately from, but has a closely intellectual affinity with, the technique of critical interpretive synthesis used in systematic reviews of health services research (2).

Hermeneutic review is an interpretive, not a technical, process. It is summarized by Boell and Cecez-Kecmanovic (1) and illustrated schematically in Fig. 1.

Research typically starts with a puzzle or a problem found in research or professional literature, through education, media, or experience in practice. A researcher then begins her/his exploration by first seeking more general introductory texts and review papers which are especially valuable. She/he reads, makes sense of and interprets these texts and finds out further relevant texts in order to identify and understand major ideas, findings, concepts and theories and establish connections among them. During this process the development of understanding progresses gradually while the researcher engages with and makes her/his own way through the literature. Initial ideas and preunderstandings are questioned, refined and extended in the light of what is being learned.

As Fig. 1 shows, the review process consisted of two interlinked hermeneutic cycles: accessing and interpreting the literature and developing the argument. Drawing on insights from the philosopher Ludwig Wittgenstein, the approach distinguishes between puzzles or problems that require information and those that require clarification and insight (1). Searching seeks to identify new information about a problem and more relevant sources of information. As authors interpret and collate these sources, they create an ever-larger set of publications, which is initially overwhelming, foreign and confusing. The more literature they accumulate, the more pressing it becomes to interpret, clarify and understand the ideas they contain (1). This feeds into the lower cycle in Fig. 1.

Fig. 1. Hermeneutic review (adapted with permission from Boell and Cecez-Kecmanovic (1))



While hermeneutic review is iterative and places high value on reflection and interpretation (processes which, because they go on inside the researcher's head, are not easy to monitor or standardize), it is not unsystematic. On the contrary, the search phase required a highly systematic process of refining search terms, pursuing references of references and tracking citations forward (citation pearl growth in Fig. 2), managing search data and reference lists, and documenting progress.

Fig. 2 More detailed illustration of the search phase in hermeneutic review (adapted with permission from Boell and Cecez-Kecmanovic (1))



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ANNEX 3. A BRIEF HISTORY OF NARRATIVE RESEARCH IN HEALTH CARE

Research into personal stories of illness has a long and diverse history (e.g. as a branch of anthropology), but the systematic study of the illness narrative by health care researchers and social scientists working in health care is a more recent development. As Arthur Frank pointed out, not only was the patient as a person absent from medical textbooks of the 1970s, he or she was also absent from sociological textbooks of the same period, which concentrated instead on the sociology of medicine as a profession (1).

Frank sought to rectify this. After experiencing two episodes of life-threatening illness himself at a young age, he wrote two books offering a theoretical (and explicitly subjective) perspective on the sociology of actually being ill (2,3). He proposed that serious illness transforms a *person* into a *patient* (territory that is colonized by the medical profession and claimed as their own) and brings a profound sense of loss; narrative is a critical tool not merely for coming to terms with that loss but (more fundamentally) for resisting entrapment by medical conceptualizations and modelling.

Along with other social scientists (4–9) and some doctors (10,11), Frank challenged the prevailing paradigm of scientifically informed evidence-based decision-making, in which every patient with a particular disease was assumed to be sick in more or less the same way. They argued for a return to a humanistic (ethical, holistic, relational, personal) paradigm. In particular, narrative could potentially surface the voice of the lifeworld (the world of home, family and community, where people became sick, experienced fear and/or hope, and strove to cope), which often contrasted starkly with the (narrowly biomedical) voice of medicine (6). Physician Rita Charon introduced parallel charts in hospital: one giving a conventional biomedical account and the other the physician's reflections on their efforts to engage with the patient's lifeworld and personal narrative (12).

These scholars also emphasized that narrative is not merely an account of a person's illness but (often) is also a component of its treatment. In chronic illness, a good therapeutic relationship, sustained over time, can allow co-construction of a healing



narrative that makes sense of the illness and supports the sick person in rebuilding his or her identity (10,11). Such therapeutic narratives have been depicted as healing dramas (enacted rather than told), particularly in fields such as rehabilitation (5).

In public health and medical sociology, individual narratives have proved to be powerful tools in the study of the social, material and environmental determinants of health, since personal stories are invariably couched within deeper, cultural narratives and folk myths (13). This application of narrative methods to capture the cultural contexts of health and illness forms the focus of the case studies in this report. Some researchers have joined an international endeavour to collect and index hundreds of illness narratives in an online database (14). Individual illness narratives collected in research studies are the first step in the construction of patient-reported outcome measures, "standardised, validated questionnaires that are completed by patients to measure their perceptions of their own functional status and wellbeing", and are used in the systematic assessment of the patient experience in both clinical practice and research studies (15).

Recent research on illness narrative (reflecting the critical turn in narrative research more generally) has viewed stories not as texts but as "social performances that are interactively constructed, institutionally regulated, and assessed by their audiences in relation to hierarchies of ... credibility" (16). These phenomena are unlikely to be elucidated in formal narrative interviews. Rather, naturalistic (ethnographic) methods are increasingly used to capture real-time, real-world talk (such as gossip and jokes) and actions – and the cultural practices that impact on health behaviours. Researchers have also begun to study systematically what is not said (the non-narrated) and what is – either deliberately or subconsciously – distorted (the dynarrated) (17).

Until recently, narrative research has focused on what individual illness narratives say about the individual. An exciting development is extending the analysis of such narratives to capture the wider cultural (meta-)narratives within which the individual's personal account of illness and suffering is nested (18).

Another emerging stream of narrative research is the study of policy discourse. Policy discourse can be thought of as a particular way of framing and prioritizing issues, which, unsurprisingly, tends to favour the perspective of those who hold formal power and who use both qualitative and quantitative evidence instrumentally to bolster a preferred storyline (19,20). As the case studies illustrate, individuals' illness narratives, couched within wider meta-narratives of their own family and

cultural groups, may clash with the meta-narratives created by policy-makers (who define problems, frame them in particular ways and designate them as high or low priority).

In recent years, researchers have recognized both the ethical and the scientific challenges of imposing their own research framing (e.g. a particular theoretical lens) on the voices of the vulnerable. Some have sought to capture a more participant-centred (emic) rather than researcher-centred (etic) account using phenomenology (i.e. the study of lived experience from the perspective of the individual) (21), co-design approaches such as community-based participatory research (22) or by focusing on naturally occurring narratives and collective sense-making in online communities (23,24) and social movements (25).

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World Health Organization

Regional Office for Europe

UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark

Tel.: +45 45 33 70 00

Fax: +45 45 33 70 01

Email: euwhocontact@who.int

Website: www.euro.who.int

