



10-19-2018

## Illness Narratives in Ethical Counseling

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### Recommended Citation

Haker, Hille. Illness Narratives in Ethical Counseling. *Illness Narratives in Practice: Potentials and Challenges of Using Narratives in Health-related Contexts*, , : 63-74, 2018. Retrieved from Loyola eCommons, Theology: Faculty Publications and Other Works, <http://dx.doi.org/10.1093/med/9780198806660.001.0001>

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# OXFORD

UNIVERSITY PRESS

Great Clarendon Street, Oxford, OX2 6DP,  
United Kingdom

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First Edition published in 2018

Impression: 1

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Published in the United States of America by Oxford University Press  
198 Madison Avenue, New York, NY 10016, United States of America

British Library Cataloguing in Publication Data

Data available

Library of Congress Control Number: 2018941860

ISBN 978-0-19-880666-0

9 8 7 6 5 4 3 2 1

Printed and bound by  
CPI Group (UK) Ltd, Croydon, CR0 4YY

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# **Illness narratives in counselling— narrative medicine and narrative ethics**

Hille Haker

## **The narrative turn in medicine**

Since the 1970s, criticism of a ‘reductionist’ approach within medicine has resulted in a return to narratives and the review of the role of narratives in medical practice. Hence, narrative medicine is part of a broader epistemological shift—medicine must complement its science-based method with hermeneutics that understand medicine as social praxis (Gadamer, 1996)—and a cultural shift that mirrors the turn to postmodern pluralism (and sometimes to relativism). Both shifts result in a new attention to experiential stories and a critique of the exclusive reign of evidence-based empirical knowledge to determine a person’s health status. Ronald Schleifer and Jerry Vannatta follow Marshall Marinter’s definition:

Disease then [ ... ] is the pathological process, deviation from a biological norm. Illness is the patient’s experience of ill health, sometimes when no disease can be found. Sickness is the role negotiated with society (Schleifer and Vannatta, 2013).

In the context of this chapter, I add a fourth category, namely ‘disability’, a specific ‘deviation from the norm.’

Medical doctor and literature scholar Rita Charon who coined the term ‘narrative medicine’ is one prominent representative of this turn to experiential competency, but given the long history of medicine and literature, for example, she is hardly exceptional in the shift to narratives (Charon and Montello, 2002; Charon, 2006). Charon aims to return the power of storytelling to the patient, shifting the emphasis to collaborative meaning-making and interpretation. This chapter argues that counsellors indeed co-construct stories and engage in storytelling, too. Charon, however, misinterprets the communicative structure of the encounter because in professional contexts, expertise, knowledge, and power are distributed differently among the partners. In a more recent work, Charon stresses the role of recognition and reciprocity (Charon, 2012). She recalls encounters with a patient she has seen over an extended period of time and argues that the patient comes to know much about the doctor’s life, too—but it is a misconception



of professional relations to assume that this fact creates a *reciprocal recognition*. In my view, Charon overstates her argument: while the understanding of disease and disability, illness, and sickness overlap in both counsellor and client/patient understanding, the very term 'counselling' constitutes their positional asymmetry regarding the knowledge about the empirical dimension of health, i.e., the 'disease' or 'disability' as medical terms. As I show at the end of this chapter, Charon is correct that doctors and/or counsellors cannot but 'reveal' something about their own selves, interpretation, and meaning-making in the encounter with their patients or clients. But this does not mean that patients or clients are interested (or should be interested) in a *reciprocal relationship* that resembles more a friendship than a professional relationship.

The relationship between counsellor and client to which I here constrain my reflections requires specific norms that ensure the respect and avoid the exploitation of a dependent's vulnerability. *Recognition* is indeed an appropriate concept for this relationship, but in its ethical dimension, it is much more complex than Charon has it. Recognition entails, first, the *identification* of the partners as counsellor and client; it entails the *acknowledgment* that both the client's and counsellor's perspective is meaningful and counts in the counselling; and it entails the *respect* for each other's rights and obligations, including the scope and limits of actions. While the counsellor has more initial agential power in the constellation, the patient or client, vulnerable because of her dependency on help, must be supported as much as possible in her agency. Narrative is one element among several others to achieve this goal; and recognition in the above-mentioned threefold understanding replaces a paternalistic and sometimes authoritarian understanding of the professional role of counsellors.

Narrative medicine has its critics, too. In his critique of the postmodern shift to narratives within the medical humanities, Seamus Mahony, for example, criticizes Charon in particular for promoting a 'dangerous' concept of empathy and understanding (Mahony, 2013). He claims that the discourse in narrative medicine is clouded in impenetrable jargon, strongly influenced by postmodernist literary theory. And much of the language employed, he argues, has a religious flavour that is uncalled for within medical communication: 'witnessing', 'professing', and 'honouring' are activities, Mahony argues, that do not belong in the doctor-patient communication (Mahony, 2013, p. 614). I echo a caution about the status of narrative medicine, but Mahony and others misplace their critique: it is due to the insufficient theory, not the concept as such, that narrative medicine is often merely used as an appeal to be more 'humane' in the context of a highly bureaucratic, technocratic, and automated medical practice.

This chapter focuses on ethics in genetic counselling and explores the role of narratives in this context. Counselling practices have been submitted to professional ethical standards over the last few decades. These are often tied to codes of conduct that professional societies developed as their ethical guidelines beyond the legal requirements. They are meant to orientate the counselling profession in their encounters with clients, colleagues, and society.



## The practice of counselling—standards and competencies

The mission statement of the American Counseling Association (ACA) states the following:

- ◆ The mission of the American Counseling Association is to enhance the quality of life in society by promoting the development of professional counselors, advancing the counseling profession, and using the profession and practice of counseling to promote respect for human dignity and diversity (ACA, 2014, p. 2), and
- ◆ Counseling is a professional relationship that empowers diverse individuals, families, and groups to accomplish mental health, wellness, education, and career goals (ACA, 2014, p. 3).

The ACA's *Code of Ethics* entails not only the broad goal of promoting and enhancing the quality of life in different social spheres, but also explicitly draws on the ethical principles of respect for human dignity and diversity. The principles echo the main bioethical principles that have been developed over the last decades, especially by James Childress and Tom Beauchamp (2012).

The National Society of Genetic Counselors (NSGC) adopted an ethics code in 1992 (with the last revision in 2006), which is more specific to genetic counselling. In relation to their clients, it spells out that counsellors are to respect their clients' 'beliefs, inclinations, circumstances, feelings, family relationships and cultural traditions' (NSGC, 2006, Section II, Nr. 3), and enable them 'to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences' (NSGC, 2006, Section II, Nr. 4). Because of the specific sensitivity of genetic information, the NSGC opposes 'the use of genetic information as the basis for discrimination' and supports 'policies that assure ethically responsible research' (NSGC, 2006, Section IV, Nr. 7).

Ethical values, norms, and principles are professional standards; they are norms that constitute 'good' and 'right' counselling. They link counselling to the overall framework of medical ethics. Comparing it to the narrative turn in medicine, the ethical standards do *not* reflect the so-called postmodern trend that has often been labelled antinormative; rather, both codes represent an ethics that is abstract, decontextualized, and faced with multiple difficulties in its application (Page, 2012). Following the mainstream Anglo-American medical ethics approaches, the ACA and the NSGC embrace the medical-ethical principles without attending to discourses that question the normative framework to which they apply; this, I argue, creates a tension for the implementation of narratives. In contrast, postmodern theorists consider the abstract normative frameworks as an obstacle to respect diversity and the multiplicities of identities. Postmodern theories of ethics, though plural themselves, emphasize instead difference, multiplicity, and the interrelation of science and society (Bauman, 1993; Harding, 2009; Reuter and Wieser, 2006). In the following, I suggest that the approach of *narrative ethics*, albeit not an approach that covers all ethical issues, can bridge the two sides: the dimension of (illness) narratives



in counselling on the one side, and the normative framework of ethics that defines the standard of a good practice on the other.

## Narratives in counselling

The question is not *whether* narratives matter in the encounters between counsellors and clients, but rather *how* they matter. Counsellors necessarily listen to clients' personal narratives to understand what matters to clients. There is an ongoing debate, however, about the status of narratives regarding its potency (or claim) to *represent* (Aristotle's term of *mimesis*) a person's 'real' life and identity. More specifically, narrative theory analyses the different ways of narration or *presentation* (Atkins, 2004). Over the last two decades, I have worked on the literary forms within the genre of (fictional) biographies and autobiographies within narrative ethics (Haker, 2006; Haker, 1999; Haker, 2009), arguing that a critical hermeneutics is required as part of narrative theory; life-stories entail *formal* structures of narratives, including life stories as a quest or journey, conversion narratives, healing narratives, or any teleological narrative of a 'good life'. These forms owe much to literary traditions of oral and written nature, and as such they must be scrutinized in their aesthetic (and social) function. Arthur Frank, for example, identifies several genres in patients' stories of illness: narratives of restitution, narratives of chaos, narratives of quest, life reviews, and trauma narratives (Frank, 1995). Interestingly, life reviews have become most prominent in hospice care (Flanagan, 2017)—their *narrative* function is dominated by their *ethical* (and *spiritual*) function, often conveyed in spiritual care concepts, to bring closure, peace, and forgiveness. It is this practice of narrative ethics that sparked Mahony's criticism of the (often unaccounted) appeal to particular forms of the 'good life' within narrative medicine. In contrast to such 'big stories' of a person's life, metaphors and 'small stories' (Bamberg, 2006; Georgakopoulou, 2007), i.e., fragments of stories that require unfolding, may be much more important *ethically*, because values, particular interpretations, and judgments entailed in them often remain un(dis)covered and hence undiscussed:

[T]he smallness of talk, where fleeting moments of narrative orientation to the world can be easily missed out by an analytical lens that only takes fully fledged ('big') stories as the prototype from where the analytic vocabulary is supposed to emerge. (Bamberg & Georgakopoulou, 2008).

Narratives are necessarily addressed, and they are necessarily mediated by the public language and public concepts of reasoning (Korsgaard, 2009). I agree with Bamberg that there is no necessity to speak of 'narrative exceptionalism' when it comes to identity (Bamberg, 2012); but it is certainly fair to say that in counselling and personal decision making, narratives and storytelling play a more important role than, for example, argumentation and democratic public reasoning. Both forms of 'communicative action' complement each other and overlap considerably: narrative and argumentative reasoning intertwine and overlap, and the practice of genetic counselling has as much affinity to narratives as it has affinities to scientific empirical knowledge. Both, however, are linked to 'sickness', i.e., the social interpretations of illness, disease, and disability. Unfortunately,



narrative theories often tend to ignore the social—and that means, among other things, the *social-normative*—contexts of personal narratives. Postmodern, poststructural, feminist, and postcolonial studies are right to criticize the lack of social analyses and the socially mediated epistemological frames of the health discourse. I would therefore caution against an uncritical reception of narratives, taking them merely as representations, rather than presentations of reality, and, likewise, caution against an uncritical reception of narrative ethics.

Against the critics of narrative medicine, however, I believe there cannot be any doubt that narrative competency helps counsellors to understand, to recognize and respect, and to empathize with clients. These required competencies call for special attention to *oral* narratives told in the counselling sessions, which function differently from written stories: oral stories can guide the understanding and interpretation through gestures, body language, spaces between sentences, emphasis, etc. (Arduser, 2014).

The 'meaning-making' and interpretation is never value-neutral. In their effort to render the evaluation as reflective as possible, Schleifer and Vandatta point to the shared enterprise of practical reasoning, including the reasoning of ethical issues, which they identify as the Aristotelian practice of *phronesis*:

The job is to listen carefully (listening for what is said and for what is not said), to facilitate the parts of the story that are not there, and to join with the patient in articulating what is important, the patient's chief concern. But the physician does not have to drive the train; the patient drives the train, and the burden for doing all the work is lifted from the doctor (Schleifer and Vannatta, 2013, p. 169).

The following section takes a closer look at ways of practical reasoning in the decision-making processes of genetic counselling.

## **Genetic counselling and decision-making in ethical conflicts**

Genetic counselling not only provides information but also supports a client in the deliberation of decisions in view of a genetic information. The models of decision-making must reflect the normative standards of the profession and hence realize, for example, the respect of dignity and diversity stated as core principles in the above-mentioned codes. Furthermore, counselling concerns *procedural* issues of decision making, such as transparency and the respect for the noncoerced choice by the clients. Counselling necessarily entails the conversation about *substantial* ethical issues, and hence the ethical values that inform the clients' choices. Since the counselling ethics standards call for an abstract and vague respect of the client's decisions, counsellors often merely apply the *procedural* guidelines and pay far less attention to the substantive ethical issues their clients are facing.

The ACA emphasizes the role of counsellors in the decision-making process:

When counselors are faced with ethical dilemmas that are difficult to resolve, they are expected to engage in a carefully considered ethical decision-making process, consulting available resources as needed.... ethical reasoning includes consideration of professional values, professional ethical principles, and ethical standards (ACA, 2014, p. 19).



Non-directive counselling rests upon this framing of moral pluralism that often translates into a liberal understanding of autonomy as choice that owes more to the Anglo-American tradition than to the Kantian understanding of autonomy as moral agency and responsibility (O'Neill, 2002). As long as the counsellor complies with the procedural rules of respect, transparency, and non-coercion, the professional standards seem to be met. Nevertheless, the ACA puts considerable weight on the counsellor to guide the process; it proposes to follow common models of decision making. It recommends the following steps, although they are not meant to be exhaustive:

1. Identify the problem.
2. Consider the standards of the ACA, principles, and laws.
3. Generate the course of action.
4. Consider the consequences.
5. Deliberate the risks and benefits.
6. Select the objective course of action based on the circumstances and welfare of all involved (cf. p. 19).

It is clear that it is the counsellor who is in the driver's seat of the process. This observation underscores the power differential or asymmetry between counsellor and client, because *how* a problem is described, for example, will determine in good part the options and choices. Clearly, the counsellor is supposed to steer the conversation. She should follow the principle-based approach of medical ethics, but there is no indication how the different principles relate to each other, how they are to be prioritized, and how one may define a 'dilemma'. Most likely, the description of the problem will be oriented by the medical epistemology: the 'problem' will then be described in terms of genetic risks. Hence, the connection between the different semantics of disease and disability, illness, and sickness is lost, and most likely, only one semantic is favoured. Narrative ethics offers at least two important corrections. First, it will reflect on *different* understandings of health and its counterparts: counsellors must attend to the personal, experiential notion of *illness* as well as to the role of social mediations in the construction, for example, of disability. Second, narrative ethics will operate with a model of shared decision making that secures the client's position as the centre of the conversation and the counsellor's role as a resource of expert knowledge, which the client does not have. In other words, narrative ethics will attend to the 'ethical dimensions' not merely as the normative principles of generalized *respect*, but also as personalized, relational *recognition* of the other who is faced with choices that are, in part, pre-structured by social norms and the genre of genetic counselling.

Already in 1986, Albrecht Wellmer stated that most ethical controversies may rest upon different analyses of situations; he therefore called for paying more attention to contextual analyses (Wellmer, 1986). In an effort to connect the hermeneutical and the normative dimension of ethical reflection, in 2002 Dietmar Mieth proposed a method, originally developed for bioethics deliberations, which he called 'conductive'—it complements an inductive, contextual approach with a deductive, normative approach. It is possible to rephrase the steps in this way:



1. Determine the pre-understanding and context of action.
2. Identify what the situation is about (facts).
3. Identify possible ethical orientations.
4. Determine alternative actions.
5. Assess the ethical priorities.
6. Implement the action.

Since Mieth developed this sequence mainly for political/social deliberations, it is only applicable with modifications. Nevertheless, it is possible to see that it would require the counsellor to attend much more to the social analysis and interpretation, instead of defining risks and benefits that are dependent on probabilistic projections and subject to plural interpretations of risk-taking. While I have previously proposed a general model for gen-ethical counselling that also attends to the evaluative and normative dimensions of ethics (Haker, 2002), here I will focus more on the role of small stories in the configuration of narratives. Paul Ricoeur's concept of a threefold mimesis, which aims to address the above-mentioned question of presentation and representation, or, in other words, the relationship between narrative and reality, stories and life, considers stories neither as a realist representation of a person's life nor as merely imagined construction that has no root in the experienced life of the narrator. Rather, the *configuration* has a *pre-figured* background in the praxis and a person's lifeworld, for example her pre-judgment of disabilities. Likewise, the story told in the counselling will *re-figure* or shape a person's understanding in the future (Ricoeur, 1988; Ricoeur, 1992). With these insights, the following steps could serve as a practical guide for counsellors:

1. Determine the context (narrative *prefiguration* of praxis).
2. Analyse the relational constellation relevant for the decision—narrative *configuration I*.
3. Identify the ethical conflict and the underlying norms (principles, standards, laws) of action in relation to the situation in question (*configuration II*).
4. Identify potential conflicts between personal values and normative principles.
5. Explore the consequences of all options together with the client (*configuration III*), support the client to determine priorities and make a decision.
6. Determine the steps of action, based upon the decision.
7. Explore with the client how to implement the course of action (*refiguration*).

This model needs to be elaborated further, and the terminology of 'sequence' must be adjusted in the real-life communications. The model is neither 'directive' nor 'non-directive' in the traditional sense, but *correlative*. It leaves room for narrative enactment and interpretation, but it has the advantage over other narrative medicine models in that it does not jump from stories to ethical assessments and decision. Rather, it correlates the descriptive and the normative dimension of ethics, with narratives functioning as a *bridge* between description and prescription (Haker, 2010; Ricoeur, 1992). Counsellors need to attend to signals that are inherent to narratives, however 'small' they are, and take them as occasions to begin the 'meaning-making' process.



## Narratives in gen-ethical counselling

Susan Markens conducted interviews with genetic counsellors to better understand their role in decision making and to explore the publicly raised concern that counsellors implicitly or explicitly encourage couples to terminate pregnancies. The question concerns the *prefiguration* of prenatal genetic counselling:

[B]y implicating their role in the normalization process, much research seems to suggest that genetic counsellors explicitly and implicitly encourage women to undergo prenatal testing and to terminate pregnancies with abnormalities (Markens, 2013, p. 434).

Her interviews demonstrate that counsellors take the medical information as guide for action—following the communicative norms of *information*, which demand ‘description’ without ‘prescription’. I have said that narratives are bridges between description and prescription, and this may often happen through ‘small stories’. Counsellors must understand, however, that it is not only their clients who step on this ‘bridge’—in entering a conversation beyond the ‘transmission’ of facts (though their communication can never be *entirely* value-neutral), they step on it, too. The counsellors’ ethical neutrality (‘be descriptive, not prescriptive’) may be especially challenged when the clients’ assessments of an ethical conflict departs from the counsellor’s own assessment. Narrative ethics, I argue, helps to better understand that the position of the counsellor as objective ‘reporter’ of medical facts is as misleading as its opposite. Yet, ‘morality’ is in fact often understood as taking a prescriptive position, rendering counsellors as ‘moral police’. In contrast to both positions, narrative ethics reflects on the encounters on the ‘narrative bridge’ exactly between description and prescription. The narrative analysis enables the ethical reflection, understood as practical reason in the above-mentioned sense. The counsellor’s concern for narrative will not *appeal* to a client’s life-story but rather attend to the ‘small stories’ that require analysis and unfolding. Markens documents the following encounter, told by a genetic counsellor:

There was one case that I remember that was—so when they measure fetal bones... so these percentiles are averages. They’re norms.... Well, I had a couple whose measurements were consistently below normal, consistently below 10%.... But not all over, and really it was just a femur and a humerus.... Otherwise the baby seemed to be growing—progressing normally, was a normal amniocentesis. There [were] no birth defects. (Markens, 2013, p. 444)

The counsellor recalls the medical diagnosis. Yet, there are two terms that entail ‘small stories’: the counsellor calls the foetus (the medical terminology) a ‘baby’ and refers to the lack of ‘birth defects’. The language of ‘birth defects’ is often used in medical information, but it nevertheless is a non-neutral, value-laden term, because it interprets particular genetic features as ‘defects’—something that disabilities studies would strongly oppose because it employs a biological concept of disability. This is how the counsellor recalls the couples’ response:

And they were really worried about having a baby who was going to be a dwarf. Even though there was really nothing to indicate.... There was a lot more leaning towards normal than there was leaning towards dwarf, and they terminated that pregnancy.



Again, the 'small story' is entailed in one word: the prospective parents identify their future child as a 'dwarf'. Identification is *one* aspect of recognition, as I have argued earlier—in this case a stigmatizing *misrecognition* that distances the prospective parents from their future child, now called the 'foetus', 'baby', or 'dwarf'. The counsellor repeats this term uncritically, merely pointing out that s/he could not convey to the clients that their evaluation does not match the *facts* of the medical diagnosis. The tension the counsellor recalls seems to entirely rest on the wrong application of a valid concept ('dwarfness') to the actual case, not on the concept itself:

And I—I didn't say 'I think you're wrong,' but I spent a lot of time being, like, 'Are you sure? Because this is a really big decision, and most likely there's really only a tiny chance that this baby ...'—and I was trying to ... and they were, like, 'Nope, nope, nope. We just can't. We can't. We're too scared.' ... And they terminated this pregnancy, and they sent the baby off for a skeleton review for skeletal dysplasia, there was nothing wrong with this baby. They couldn't find anything. So they most likely terminated a very normal pregnancy. ... I had a really hard time with that one because ... I don't know. It was just so hard because there most likely was nothing going to be wrong with this kid, but how do I know. ... But it's those, like, sort of soft calls where you're, like, come on (Markens, 2013, p. 445).

The counsellor disagrees with the couple's ethical assessment and subsequent course of action, the termination of pregnancy, expressed in the repeated use of the term 'baby'; but s/he also feels bound by the ethical principle of non-directive counselling that prohibited counsellors from becoming prescriptive. Yet, his/her retrospective attitude is clearly disrespectful of the clients: 'But it's those, like, sort of soft calls where you're, like, come on.'

My proposed model of ethical decision making would start with the one-word small story: it would require the counsellor to unpack the term 'dwarf' (Step 1) and its underlying social imagery. S/he could explore how the prospective parents imagine their child, giving them the opportunity to speak of their own desires, imaginations, and anxieties. The counsellor could emphasize the different layers of non-health, i.e., disease and disability, illness, and sickness—including the tension between the medical and the social concept of disability. S/he could address the tension between what they assumed to be an existential threat and the medical findings (Step 2). S/he could ask questions and interpret the (small) story, thereby co-constructing a narrative that addresses the moral emotions relevant to the conflict (Step 3). Potentially, even the concept of parenthood and the concept of recognition—as acknowledgment and respect as process in addition to a static identification—could become part of the conversation (Step 4), making the tension of the ethical assessment a part of the conversation, rather than evading it. Step 5 could allow for more imagining of the future—inquiring how the clients envision their life with their future child, or after losing it under the given circumstances. Step 6 would follow the ACA, assuring the clients that it is up to them to make the best possible decision within the legal constraints.

My model creates both more space for the narrative and hermeneutical work of meaning-making and space for the ethical deliberation. This does not mean that the counsellor uses his or her power to *judge* the values or tries to convince the clients of his or her own ethical values; rather, it means that counsellors understand that ethical deliberation is part



of the interpretation and co-construction of narratives. Learning to identify and analyse such 'small stories' must be part of the education and ongoing training of counsellors.

The model does not depart from a non-directive approach. But it would not suppress the conversation about moral judgments (including the prejudgment of the prefiguration of narratives in the lifeworld) and explicate them in order to reason about them. It would enable counsellors to concretize their professional ethical standards, in reflecting upon the medical terminology, their own pre-judgments that they necessarily enact in conversations, and potentially in correcting (denigrating) imageries or attitudes they may hear from their clients. Narrative ethics examines all stories critically, considering medical information *and* ethical concepts that the counsellor must have available. While narrative ethics cannot *resolve* the tensions, it may clarify the role of counsellors in the ethical decision making, attending especially to the theory of oral narratives and the theory of 'small stories' that accompany oral narratives.

## Conclusion

This chapter argued that narratives play a role in counselling, 'no matter what'. Counsellors must acquire the competence to understand how stories entail moral understandings. At times, these may be in tension with the ethical principles counsellors stand for as a profession, namely to respect the dignity and diversity, well-being, and social justice of all people. I am not following postmodern ethics approaches, but I echo the critique of 'principles' when they are merely used as a normative fig leaf with no practical impact. Narratives, I have argued, are the bridge between descriptions and prescriptions; their function is hermeneutic, i.e., to discern the (necessarily) evaluative understanding of reality, experiences, and social contexts. Narrative ethics defends an ethics approach that takes narratives and principles as complementary, i.e., correlative, corrective, and constructive resources in ethical decision making—but it also upholds the obligation to respect and recognize the concrete 'other'.

Acquiring competence in narrative ethics involves much training in narrative theory as well as in ethics. The model proposed here needs to be tested and further developed in the professional education and training forum. But in my experience, the 'gen-ethical' model is better than the one implemented by most genetic counsellors. The standard models leave little room for either narrative competency or ethical deliberation as a collaborative endeavour between counsellors and their clients, and therefore remain abstract and often purely rhetorical. Recognition, spelled out as *respect*, obliges the counsellor to take seriously the client's agency, capability, right, and responsibility to make decisions (Ricoeur, 2006). Recognition, spelled out as *acknowledgment*, however, requires that the counsellor attends to the concreteness of the 'other'. It requires a critical listening and 'unpacking' of the 'small stories' that are rooted as much in the social lifeworld as in the personal lives of the clients. After the process of having 'all things considered' collaboratively, counsellors will be better able to leave it to the clients to make their decisions.



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