

# Narrative ethics in nursing for persons with intellectual disabilities<sup>1</sup>

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## Abstract

Both in the Netherlands and in Britain, practices of 'life story work' have emerged in nursing for persons with intellectual disabilities. The narrative approach to care and support may at the same time be considered as an attempt to compensate for the 'disabled authorship' of many persons with intellectual disabilities and as a sign of controversy with standard practices of diagnosis and treatment that tend to neglect the personal identities of both clients and care givers, their particular historical and relational contexts and their spiritual needs. This paper argues that narrative ethics not only offers an appropriate moral framework for practices of life story work, but that these practices are a narrative ethics in action. Starting with an account of the concept of 'life story work' as it has been introduced in nursing practices in the field of intellectual disability, the paper explains its relationship with key characteristics of narrative ethics. The teleological dimension in narrative ethics and in practices of life story work sparks off a dialectic process of understanding of the client and self-understanding of the care giver. It also invites a respect for life in its openness toward the future and presupposes an openness toward other possible versions of the life narrative. The phenomenological and hermeneutic-interpretative methodologies in narrative ethics aim at a 'sudden moment of intimacy' in relationships of nurses and clients. The 'epiphany' of this essential moment of recognition, insight and engagement cannot, however, be brought about by methodology.

*Keywords:* narrative ethics, life story, nursing, methodology, moral theory, hermeneutics.

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<sup>1</sup>An earlier version of this paper was delivered as an invited keynote lecture at the 8th International Philosophy of Nursing Conference 'Nursing Practice and Moral Theory', University of Wales Swansea, September 2004.

## Introduction

For the greater part of my life I have been working as a chaplain in institutions and group homes for people with intellectual disabilities.<sup>2</sup> In that context I have met quite a lot of people who were either unable, or only to a small extent able, to tell me about their lives. Often, they were surrounded by professional care givers that also did not have any knowledge of their clients other than the information they had read in files and records and their own experiences with the client. In critical situations, or situations of uncertainty, a lot of 'archaeological' digging had to be done in order to get the nearest glimpse of a bigger picture of the client: his or her past; his or her preferences; his or her own ways of making sense of life; his or her significant others.

The most acutely embarrassing experiences of lack of knowledge of the uniqueness of clients often occurred when I was invited to present a short life story at the memorial service after the death of a client. Listening to or reading that life story more often than not evoked feelings of recognition and surprise in the audience, especially in the professional care givers. They often told me that listening to the story changed their view of the person who had died. It had shed new light on their relationship to the client. Sometimes they even said that in many cases they would have acted differently if they had known what they learned now. Somehow, a new way of seeing their client was triggered by the life story. From the narrative form in which they had been faced with the life of their client there seemed to emerge a coherence and meaning that hitherto had remained out of sight (Meininger, 2000).

These and similar experiences crystallized to form a number of challenging questions: 'Could we express and represent the life story of a client already during the course of his or her life, in the middle of day-to-day companionship, care and support?', and 'How could writing, re-telling, reading and discussing these life stories incite a renewal of

views, relationships and actions?' Attempts to answer these questions have led to practices of 'life story work' in which 'life narratives' and 'life story books' are used as a resource in care and support for people with an intellectual disability (van Oosterhout *et al.*, 1996; Hewitt, 1997, 2000). This interest in life story work is also found in other areas of health care and welfare work such as in care for the elderly and psycho-geriatrics (Viney, 1993; Blimlinger *et al.*, 1996; Breed *et al.*, 1998; Huizing *et al.*, 2001), in child protection and foster care (Ryan & Walker, 1999), in social work (Usher, 1999), in psychotherapy (McLeod, 1997) and in medical education and care (Montello, 1995; Hudson Jones, 1997). This attention to narrative approaches is part of a growing trend over the last 20 years in which (life) narratives are regarded as an important means of access to knowledge in human and cultural sciences (Polkinghorne, 1988; Ankersmit *et al.*, 1990), including the fields of history, philosophy, theology (Nelson, 1987) and bio-ethics (Brody, 1997).

In this contribution, I will argue that some practices of life story work are expressions of a narrative ethics. The phrasing of this last sentence already manifests three important lines of thought. The first is that in my view not all practices labelled as 'life story work' can be seen as such an instance. The second is that there are several forms of narrative ethics. And the third is that the narrative ethics I am talking about is a moral practice and a process rather than a system or a theory, though it has closer connections with virtue ethics than with other moral theories. I will start with an account of the concept of life story work as it has been introduced in nursing for people with intellectual disabilities. Secondly, I will give an account of narrative ethics in its relation to practices of life story work. Thirdly, a methodology of narrative ethics will be set forth, leading to a characterization of narrative ethics as an ongoing attempt to find a 'better story'. Finally, I will point at a pitfall in and a boundary of narrative ethics.

## Life story work: definition and aims

A review of Dutch and English literature on life story work in care and support for people with intellectual

<sup>2</sup>In using the term 'intellectual disability' I follow the terminology adopted by the International Association for the Scientific Study of Intellectual Disability (IASSID).

disabilities that recently has been conducted showed a remarkable lack of terminological clarity (Meininger, 2003). When people are writing about 'life story work' in a general sense they include all those activities that propose to

- reconstruct and make a written record of (components of) a life story and/or the compilation and keeping of a life book;
- retell, study and discuss life stories and life books in contacts between persons with intellectual disabilities, their relatives and friends, care givers and others;
- promote a continued effect of the information collected in these activities on the attitudes and acts of the persons involved in everyday care, support and treatment.

This still is a rather formal and external definition of life story work. In order to get a better picture we have to extend our attention to the aims or functions that are ascribed to practices of life story work. The most general aim of life story work is connected to intellectual disability as such. The story of growing children is at first entirely the story of their parents who look ahead to the future independence of their child. Gradually children take on the authorship of their story. However, in the case of children with an intellectual disability, authorship will not be taken over in that way, '... they will never wholly become the writer of their biography and in the case of a severe disability not at all' (Reinders, 1996; p. 11). For an image of their identity persons with a severe intellectual disability are for the greater part dependent on others who in their name put their life story into words and who keep the communication with others open (Hewitt, 1997). So the general aim of life story work is to compensate for the disabled authorship caused by the sometimes severe intellectual disabilities.

Within practices of care and support, an important question for many nurses and other service workers is where and how to make room for the unique, individual perspective of the person with intellectual disabilities. This 'own perspective' should not be understood in terms of individual preferences or in terms of contentment with one's own life and with the

care offered, as it is charted by means of quality of life research. It regards a dimension that is expressed in different ways in the literature about working with life stories – 'the human being behind the disability', 'the essence of a person', 'the unique individuality', 'the meaning of feelings and life events'. Life story work is supposed to be important in order to get to know the *personal identity* of the person with a disability, at least in those aspects that are not being expressed in files and care plans. Hewitt argues that the material recorded in dossiers and care plans almost always bypasses the personal identity of the client. 'In theory ... it may be possible that two people could have an almost identical care plan (if, for example they both have the same type of cerebral palsy)' (Hewitt, 1997; p. 45). In life stories, on the contrary, the attention is focused at the individuality, at the '*who* of the client him or herself' (NZf *et al.*, 1994, p. 19) in stead of his or her *what*. It is said that life books help to get to know 'the person behind the disability' (Voortman & Scheres, n.d.; p. 1). The fact that someone's identity is continuously developing and the way in which that development is achieved may also become visible. Life story work with persons with severe intellectual disabilities will be helpful in obtaining some idea about the individual personality of the person and about the subtle ways in which it manifests itself (Hewitt, 1997).

By developing an understanding of the significance of experiences that have taken place in the distant or recent past, an insight is also gained into the way the personal identity connects to the identity as a member of a family, a circle of friends, a social and relational network. In their limited or absent attention to personal identity, the usual forms of registration and documentation in files and records often ignore the fact that others coconstitute the identity of the client. As a result a large part of the *relational context* is kept invisible to the professional care givers. If its significance cannot, or can only with great difficulty, be put into words by the client, the outcome may be – and more than often is – that the social context of that person's thinking, speaking, feeling and acting is totally overlooked. A life story on the contrary is pre-eminently a story about relationships to others, in a feeling of unity, in friendship or intimacy, in aversion

or indifference. It is a story about the changes to which these relationships are subject. A life story does not exist outside the intense intertwining with other people's life stories. In remembering, writing or retelling life stories, the significance of such relations can come to light.

Another aim of life story work has its roots in the context of spiritual care and concerns the attention to *experiencing the sense of life* and to questions concerning the *meaning of life*. According to Habraken (2000), life stories alert the sensitivity to feelings, meaning and relations and connect these to the cultural and religious context that colours and directs the life of the client. Life story work and its inherent focus on personal identity and relational context is therefore intimately connected with attention to the ways in which a client perceives sense or lack of sense in past events, present experiences and future dreams, in his or her perception of self and of people and things in his or her surroundings, in the way he or she perceives suffering and powerlessness, in his or her perception of God (NZf *et al.*, 1994; Peters, 2001). A good life story brings to light the depth dimension in someone's life, 'that what is sacred to a person' (Van Oosterhout *et al.*, 1996; p. 15). It is an important expression of the way in which the client deals with the questions of life – Who am I? Where do I come from? Where am I going? What frightens me? How can I gain confidence in the future? What will happen when I am dead? Why is there so much misery in the world? Why did this have to happen to me? (NZf *et al.*, 1994; see also Brongers, 2001). To put it briefly: life stories express the spiritual needs of people with intellectual disabilities, an area which according to recent British research has been grossly neglected (Swinton *et al.* n.d.).

Various kinds of significance have in the literature been ascribed to life story work: its significance for clients, for care givers, for practices and organizational structures of care, and for the public perception and acceptance of people with intellectual disabilities. Many elements and aspects are implied in what has been argued thus far and in what will follow. For the moment though, it may be sufficient to conclude that life story work is a compensatory practice: it is aimed at compensation of 'disabled authorship' by getting

to know better the personal identity of the client, his or her relational context and ways of making sense of life and of crucial life events.

### **Narrative ethics and life story work**

It is now time to turn our attention to narrative ethics. As I stated before, narrative ethics is part of a broad current in human and cultural sciences in which ways of narrative approach are exercised (Ganzevoort, 1998; pp. 7–28). What is labelled as a narrative ethics, however, may greatly vary and many accounts of narrative ethics are not at all clear about this (Widdershoven, 2000). On the one hand, this variety is connected with different conceptions and forms of narrative. For instance, narrative ethics may be focused on narrative as text or on the act of narrating, on fictional or on non-fictional narrative, on expressive-experiential forms of narrative (life stories) or on cultural-linguistic forms of narrative (stories and myths of religious and cultural traditions). On the other hand, this variety is connected with different uses of narrative. Narratives may be used as a resource for literary, psychological, sociological, anthropological or ethical research and analysis, as an instrument of medical education, of moral reflection or of psychotherapy or they may be seen as vehicles of human encounter and communication (Martin, 1986; Ellos, 1994; Newton, 1995; Lindemann Nelson, 1997; Chambers, 1999). And finally, within narrative ethics theological and philosophical approaches may be distinguished (Nelson, 1987; Fisher, 1987; Levine, 1998).

For the purpose of my argument, I will not go into the details of these different and often mutually enriching approaches, but merely state that my focus will be on the act of narrating and interpreting non-fictional expressive-experiential stories, an act that is primarily seen as an exemplary mode of human communication. This statement, however, leads me to mentioning one distinction that is important for our understanding, the distinction between a constructivist and a social-constructionist approach of narrative. Within the constructivist approach narrative is seen as a representation or map of the inner world of an individual, a cognitive script that is the output of

information processing in the brain of an individual. Within a social-constructionist approach narratives develop in processes of interaction between narrators and listeners. This implies that in this approach discourse and conversation are important notions. Self narratives or life narratives are seen as social constructs that are embedded in social-cultural narratives expressing the foundational values and ideas in human reality (Boeckhorst, 2001). We shape our stories even as through them we are shaped (Barbieri, 1998; p. 366). In this approach, narrating, writing and interpreting are seen as social practices (Middleton & Hewitt, 1999).

### Rational agents and persons in communion

Narrative ethics is a reaction to a form of ethics that has been conceived in an analogy to the empirical-rational conception of science (Williams, 1989). In that view, the relationship between ethical theory and moral judgement is presented as being analogous to the one between scientific theory and factual knowledge in the natural sciences. Moral judgements could in consequence be justified on the basis of the general principles of a normative ethical theory (Noble, 1989). Rationality is seen here to be without context, raised above and disconnected from culture, history or tradition (MacIntyre, 1988). It is the rationality of natural law, of the categorical imperative, of the ethical principle. This decision-orientated and action-orientated view of ethics is criticized for its alienation from the human self that has interests, that has entered into relationships, and that is situated in a social, cultural and historical landscape. In this view the person becomes a disembodied, abstract and interchangeable subject of action or treatment. The application of rules in individual situations has an instrumental and non-personal nature.<sup>3</sup> It is based on an epistemological paradigm that has been described with concepts like 'institutional, bureaucratic, central-

<sup>3</sup>In the field of psychology, Carol Gilligan's work (1982) sparked the feminist interest in narrative ethics by calling for a more 'contextual and narrative' approach in opposition to Kohlberg's 'formal and abstract' way of deducting conclusions from a hierarchical ordering of moral principles (McKinney, 1995; p. 342).

izing, general, foundational, data-oriented' (Allen, 1993). To put it briefly, narrative ethics opposes the tendency of moral theory to portray the agent in terms of a detached, purely rational will, it opposes its ahistoricity and its exclusive focusing on universal moral principles and rules (Barbieri, 1998; pp. 363–365).

Hauerwas & Burrell (1989) propose a different view. They contend that there always is a person at the origin of structural acts. This subject, character, person cannot exist outside a story regardless whether the person is the hero or the victim. In stories there is no question of causality but of a plot, a point or an intrigue. A plot meets the need to tie together 'whatever is scattered' (Ankersmit *et al.*, 1990; p. 93). However, in a plot the events are not connected by patterns that can be explained within the framework of a theory, but by motives, reasons, considerations, memories, impulses and contingencies. Life narratives transform the mere succession of events into a configuration and thereby reveal an ongoing quest for coherence, consisting in attempts at finding new approaches to self, other, meaning, value, to 'being good' (Linde, 1993). Narrating, writing and reading therefore offer resistance to the statement of the pub-goer who, before taking his first drop, sighs: 'Life's just one damn thing after another' (Holmes, 1997; p. 35). Stories are not based on abstract interchangeable actors who solve moral dilemmas by applying general principles to isolated situations and decisions. Stories tell about concrete, singular and unique characters who, closely connected to the context of their culture, their tradition and their personal fortunes, are searching for 'a good life, with and for others, in just institutions' which according to Ricoeur (1990) is the aim of ethical reflection. In this way stories may sometimes help to solve moral problems, but their principle aim is to explore moral problems rather than to solve them.

Narrative ethics is not intent on a morality of constraint, searching for the boundaries of what is permissible or what is improper. On the contrary, it embodies a 'morality of direction' in which the central question is: what is the good that should be aimed for and what personal dispositions and acts respond to the quest for goodness in the circum-

stances in question? In this view, ethics is not (or not only) the preceding deliberative procedure or the *post hoc* evaluation of selected moments of practice; rather ethics is what constitutes each moment of practice (Frank, 2002; p. 222). In a life story a person is presented or presents himself as somebody who undertakes a moral quest in his own way, closely connected to the context of his history, his tradition, his feelings, obligations and responsibilities, a person who in doing so gives sense and meaning to his existence. The question of 'what is the good that I must do?' can only be answered if first another question is answered: 'Of what story or stories am I a part?' (MacIntyre, 1984; p. 216). In each told or written (life) story the question comes up: What is the meaning of events, relationships, experiences and feelings to the main character or characters. What matters, what events, what relationships, what obligations give form to a good and meaningful life? How do the various conditions relate to each other and to what extent is their evaluation shared with or at least recognizable to others? The narrative approach in ethics is an approach that directs its attention to the particular character of concrete actors and concrete recipients. As the Belgian philosopher Arnold Burms has stated (1996, p. 94): 'It is to concrete others and not to a universal essence that we are directed in our moral involvement'. In addition, in narrative ethics the particular meaning of behaviour, feelings and events is not ignored by fitting them into theoretical schemes or causal explanations. Their meaning only comes to light if and when they are considered in the existential, relational and historical context of this concrete character. The searching and sense-giving nature of human life as well as its vulnerability and finiteness are especially recognized as relevant objects of reflection.

As the quest for the good life takes the form of a story, the narrative conception of ethics is strongly connected to a conception of narrative identity (Hauerwas, 1973; Crites, 1989; Ricoeur, 1990; Dunne, 1995; Rasmussen, 1995). In this conception the self is constituted by the other and by the vicissitudes shared with others. It is a self that discovers itself in a history, finds its identity by a detour through the other. The man that tells me about his decision to

send his child with intellectual disabilities to live in a special hospital, is also telling about his relation to other people. He is not an isolated individual: he is a son, brother, husband, father, friend. The road to myself is a road that inevitably runs by the other. and the other is always somebody who, like me, tells who he is, among other things through his story about his relation to me and to others. It is only in the community of narrators that the individuality of each self is brought to light, while on the other hand any communion between people can only be conceived of in narrating one's own story and communicating about it (Meininger, 1997; pp. 70–74). Telling stories thereby presupposes mutuality and invites a dialogue.

### Meaning and 'the good life'

Ricoeur calls the story a 'laboratory of meaning'. This not only applies to the story that originates in the literary imagination. The fictitious story, because of its being distant from every day life, creates a free space where playful experimentation is possible with life plans, acts, ethical demands, desires, professional rules, social customs and personal values (Ricoeur, 1986b, p. 220). Reading literary works evokes a heuristic framework of meaning. The same heuristic movement can be traced in the narrating and interpreting of the life story of every real person (Widdershoven & Smits, 1996). Even if it is true that man's existence is considered to be orientated toward a good life, the practice of moral life is rather a matter of tensions, differences and breaking points than of rationally argued solutions guided by general moral principles. Narrative ethics is not primarily about deciding what is the correct way to act according to abstract ethical rules, but rather about being good, 'in the right way at the right time in the right images and the right tone, with the right precision of bewilderment' (Nussbaum, 1990; p. 165).

The teleological framework of a quest for 'the good life' as it is revealed in a life story has three important implications. First, it invites to an ever renewing and deepening understanding of the selves of all the persons involved in the story – narrator, listener, author, main character and reader. This movement toward a better understanding of self, others and the world is

particularly important in care and support. Stories invite us to that process of understanding. In the story of or about a person with intellectual disability, the care giver is confronted with the complex intermingling of 'what' the client is and 'who' the client is (Isarin, 2001). That will touch the care giver immediately in her involvement with the other, and at the same time in her involvement with herself. It moves, it appeals, it demands an answer. If I have to describe who a client is, I will have to tell about my experiences with him or her. In that way I am at the same time telling his or her story and mine. I am telling how I have come to new ways of understanding myself and my own behaviour. Then I am not distancing myself from the client and I do not describe him or her in formal and abstract categories. Then I do not restrict myself to diagnosis, crises, incidents or intervention plans. Then, the idea of my experiences, attitudes and actions being exchangeable with those of others is nonsense. Telling and reading life stories of clients presuppose personal involvement and invite personal involvement. That is the strength of life story work. It pre-eminently creates a sense of equality. The other holds up a mirror to me and confronts me with the question of how I tell my own story, what the good life is to which my story is orientated and how that story relates to stories of others, in particular the story of this person who is my client.

Secondly, the teleological dimension of life stories invites to respecting life in its openness toward the future. Even the biographer will find that in going back in time the object of his biography was somebody who found his identity by looking back at a well known past and looking forward to an unknown future (Holmes, 1997). Consequently, narrating stories implies a certain way of handling time – it is aimed at a consonance of past, present and future, of memory, consciousness and expectation (Ricoeur, 1986a). Life stories are not just about the person one is or has been, they are at the same time about becoming the person one wants to be.

Thirdly, the teleological framework presupposes an openness toward other possible versions of the same life story. The story I tell about myself and others may be wrong, it may be a form of self-deception. It can become a prison if somebody gets stuck in petrified

patterns like 'the autistic' or 'aggressive behaviour'. Isarin calls this 'institutionalized narrativity' (Isarin, 2001; p. 120). But even when the story is not stuck in such stereotypes, other perspectives on the same life remain possible and it continues to be worthwhile to put the other perspectives into words. Therefore, a crucial element of a narrative-ethical approach is its dynamic-dialectic character. A story is always 'open'. Narrating demands continuing the story, listening leads to renewed listening, the written word asks to be rewritten, reading invites rereading. Interpretation is a stimulus for renewed thinking about what has become 'ordinary' or 'standard' or about what is marked as 'strange', 'different' or 'deviant', 'possible' or 'impossible'. Of course, fixed measures to test the plausibility or validity of different and multiple perspectives are not available. It is only possible to enter into a continuing dialogue about what the 'better' story might be, without being able to point to solid criteria for its being better. Nevertheless, the interpretation and imagination that are part of narrating life stories, writing them and dialoguing about them are not considered to mutilate 'reality' but rather are seen as unique forms of communication in which the identity of the person and its search for the good life are realized.

### **Narrative ethics and standard care practice**

Personal identity of both care recipient and care giver, relational context, dialectics of understanding the other and self-understanding, attentiveness for questions of meaning and coherence, openness to the future and invitation to dialogue: these elements are central in narrative ethics. It is exactly these elements that move care givers to provide room in their practice for life story work in their care for people with intellectual disabilities. We now may be able to understand why, from a perspective of narrative ethics, life story work cannot be seen as a 'neutral' technique that needs its ethical aspects studied more closely. Life story work is in itself an activity of moral imagination and ethical reflection. At the same time it reflects an epistemological paradigm and a conception of personal identity that differs significantly from standard types of acquiring knowledge and the

empirical and rational schemes of interpretation that are applied in professional nursing for persons with intellectual disabilities. The documented, analysed, and planned life as it is laid down in files and care plans generally lacks attention for the personal identity of the client who more than often is not able to express this identity without help and support of others. It is concentrated on the here and now of diagnosis and treatment, and is not interested in the client's remembered past and imagined future. Also missing on the whole is the invitation to dialogue, self-reflection and ethical reflection. Standard explanatory models show little openness to alternative approaches. As a rule, the treatment models are only related to partial aspects of a person's existence. A plurality within one perspective or of different perspectives is a phenomenon that it is not easy to come to grips with in standard practices of acquiring knowledge and the professional care and support based on it.

### Methodology of the non-enforceable

In an effort to deepen our understanding of narrative ethics I will give in this section an outline of some methodological features of narrative-ethical reflection. Gwen Anderson (1998) points to the particular layering that in a methodological respect is characteristic for the narrative-ethical approach as it finds its expression in life story work in the context of professional care.

In the first place there is the matter of descriptive phenomenological methodology. This aims at an authentic, understandable and accessible story, a 'thick description' that presents the lived life of the principal character coherently and evocatively. No account is taken of the origins and causative explanations of the experiences that are represented in the story. This kind of explanation belongs to the field of the various branches of science.

Secondly, it concerns a hermeneutic-interpretative methodology which aims at the realization of an understanding of the life story that will invite new participation in meeting the main character. A hermeneutic method as explained by Anderson contains the following components:

- Explicating the interior dialectics of the life story (coherence between component parts and the whole; distinguishing episodes);
- Exploring the 'world' that becomes visible in the use of language and metaphor;
- Starting up a dialogue by way of rereading, rethinking, listening once more to the information that is available in addition to the life story, and that may suggest reformulating, reorganizing or making different choices;
- An epiphany – a moment of recognition, insight and engagement, which cannot be forced but is nevertheless essential. It brings to light a particular value and a meaningful significance of what seemed very trivial at first sight, or it opens up the 'ordinary' meaning of behavioural expressions or experiences that seem very strange when first encountered, as it often happens in life stories of people with an intellectual disability, and in this way brings into view unthought of possibilities for an encounter. Reading a life story ideally evokes this type of a 'sudden moment of human intimacy'. In the third place Anderson distinguishes a narrative-ethical methodology in which both methodologies mentioned above – the phenomenological and the hermeneutic-interpretative – converge and are completed. As Ricoeur (1986b) has pointed out, the act of reading is only completed in a new engagement with reality. This narrative-ethical methodology has two facets. On the one hand narrative ethics encourage people to tell their own story, even if the story is horrible to hear. After all, narrating promotes self-knowledge and self-esteem. Telling a life story may result in a fuller understanding of the subject's moral qualities and opinions and the collective memory of the listeners may be completed with the necessary memory of what one would prefer to forget (Atkinson *et al.*, 1997, 2000; Kearny, 1999). This remembrance may structure conceptions about the future. At the same time narrative ethics invites people to listen to what moves people to doing what they do and being who they are. Their 'narrative of moral values' (Walker, 1998) provides an insight into their motives and passions, their love and hatred, their hopes and fears, their pride and their prejudice. It leads to a better understanding for all the unsaid and unsayable, for all that is called ethical or unethical.

cal, reasonable or unreasonable, in short, for everything that gives sense, colour and taste to life.

I would like to add two comments to Anderson's argument. In the first place she should not be read as giving a description of a methodology in which purposeful acts take place in an orderly fashion – first describing, then explaining, finally ethical analysis. It is important to hold on to the thought that what is explained here in a philosophical mode is nothing else but an indication of aspects that in practice are inextricably intermingled. In narrating, writing and reading description, hermeneutics and ethics are closely interwoven and interdependent. A second comment concerns the moment of epiphany, the moment that the Dutch poet Koplund described as the 'sudden opening of the lock' (Koplund, 1995; p. 5). In the unenforced and unenforceable nature of that moment, in its 'gift-like' character, lies the distinctive difference with functionalistic and interventionist approaches which aim at the construction of preconceived goals. The narrative approach draws life from the experience of disclosure but it cannot bring about this experience. The life story, the way it is read and the engagement it evokes thus are not the result of a method, but methods are the consequence of good stories and good readings of them (Ankersmit, 1996; p. 234). Life stories and readings of them are 'good' if they express better than other stories and readings the wholeness and uniqueness of a person. In this case the comparison with a work of art is valid.<sup>4</sup> The aesthetic experience is decisive for the quality and lasting significance of a work of art. It precedes the methodical analysis of brushwork, composition, choice of colours and theme. The methodical analysis follows the experience. It helps understand what preceded the epiphany, not to give an explanation of what caused it and even less to bring about or reproduce this 'sudden moment of human intimacy'. This does not mean that methodologies of narrating, listening, writing and reading are not important. It means that pre-eminently they should be seen as exercises in

equality, involvement and humanity. They are never ending exercises in esteem for the other that at the same time clear the way to self-esteem. They form a basis for, and guide to, the experience of really meeting the other person. Nevertheless, they can never actually produce such a meeting.

### Finding a 'better story'

In care and support for people with intellectual disabilities, nurses are readers and often also writers of life stories. Life story work opens for them the door to the world of the client and invites them to enter as guests. In other words, they are invited to enter into a relationship to that world that is respectful and personally and deeply relevant. The question is not whether the representation in the life story is the right one or whether it expresses true propositions in terms of the epistemological norms in standard scientific research and the professional care based on it. Rather, the question is whether it invites new forms of telling the story, forms in which the essence of the central character, his or her nature and identity, his or her interweaving with a network of relations, his or her unique way of making sense of life, his or her appeal to care givers presents itself more adequately. The narrative approach effects a 'dialogical spiral of relistening, resaying, rethinking and rewriting' (Anderson, 1998; p. 178) that induces a many-voiced conversation.

The text of the life story therefore is only a temporary anchorage on the journey that the main character, the people providing information, authors and readers undertake together in narrating, writing and reading. It is a stage in a continuing process of interpretation. The way the story is told now will no longer be the way it will possibly be told, written or read in a number of years. Parents now speak in a different way about their child than they did 10 years ago and they will be speaking about him 10 years from now in a different way again. Tomorrow something may happen that forces one to correct the story, that forces people to look in a different manner at the past and the future and that necessitates them to tell, write or read the story again. In any methodology of life story work justice has to be done to this principle of openness of a *sens se faisant* ('meaning under construc-

<sup>4</sup>Both Barbieri (1998) and Frank (2002) also point at the coexistence of ethics and aesthetics in narrative.

tion'), a meaning which dialectically develops itself (Tengelyi, 1998, p. 31).

Narrative ethics therefore is an exercise in moral discipline that consists in a continuous invitation to a new way of looking at and listening to clients and a new respect for clients and to a quest for the 'better' story. There are no set rules for such a better story as I already indicated. There are, however, a number of possible check points. A first check point could be the consensus between those who are narrating, those who are listening and those who are reading about the meanings enclosed in the story. Life story work is always done in the context of association and dialogue with the person with intellectual disabilities, his or her relatives, important others and one's fellow care givers. A second check point can be the coherence with earlier stories. Is the new view and the acts that follow from it in line with the personal identity of the author or central character as it was recognized in the past? Next to these formal check points it may also be a matter of testing the contents. In that case the question may arise to what degree the content of the life story corresponds with views of the future and aims in which the good life is imagined and conceptualized according to a comprehensive moral, religious or cultural tradition.

All three points presuppose a process of dialogue that is made up of awareness, clarification and change of the self-image of the people involved, in particular the professionals, and in nurturing their capacity for being touched. In that sense narrative ethics facilitates the relationship between client and care giver. In most current instrumental professional frameworks and in the technocratic management regime of today's professional care this relationship is hardly seen as a relevant theme. However, as long as nursing implies entering a relationship that fosters the restoration to a meaningful life, this relationship is its ultimate moral resource. Narrative ethics as it is practised in life story work is a continuing quest for this moral resource.

### **Conclusion: a pitfall and a boundary**

In this contribution I have not entered technicalities of narrating, writing and reading in relation to nurs-

ing and I have not entered the qualities of narrative intelligence and hermeneutic competence these activities require from professional care givers. Neither did I go into questions of authorship and coauthorship which are crucial when we are called to compensate for the disabled authorship of others (Newton, 1995; Thomä, 1998). These matters clearly deserve further attention. To conclude I just want to point shortly at two important aspects that have to be kept in mind.

The first aspect concerns the paradoxical nature of a narrative approach (Ankersmit, 1990). On the one hand, life story work has been developed as an alternative to the regular ways of acquiring knowledge and usual standards of support and care. On the other hand, people want this alternative to be recognized and embedded into existing procedures and standards. This, however, may result in a one-sided concentration on what has been written. We must be aware that writing a life story always to a certain extent implies an activity of objectifying. The text may become a 'thing' that allows itself to be manipulated and that can be used in the framework of an instrumental scheme of aims and means. It can be turned into a contribution to a 'tyranny of professional discourse' (Gillman *et al.*, 1997) that tends to undervalue or neglect any knowledge that does not fit in with the dominant tenets of a profession, an organization or leading cultural and societal ideals. If that happens, a life story will at best play the role of 'source of information, as material for professional decoding and analysis, not as a means of individualising' (Kunneman, 1995; p. 64). Narrative ethics as it is practised in life story work is always vulnerable to the delusion that scientific method could tame ordinary narrative into testable hypotheses (Bruner, 2002). Reducing the particular life story to generally accepted diagnostic or therapeutic frameworks must be typified as 'narrative denial and dispossession' (Kunneman, 1995; p. 75). In the reduction of knowledge involved, turning the narrative into something that is timeless, universal, causally connected, predictable and applicable, the lived reality of the client – daily, historical, private – falls by the wayside. Whatever has been written may soon become a file and may start functioning as such. This obliterates the

significance of speaking and listening and writing that precedes the text. It also obliterates the experience of reading, of the 'world' that is invoked by the text and of the new engagement that may be its result (Meininger, 2002; p. 133). It will inevitably lead to a disavowal of the uniqueness of personal identity. That is why I started this contribution by arguing that not all practices labelled as 'life story work' are expressions of narrative ethics.

I conclude that narrative ethics essentially finds its expression in speaking, listening, writing, reading, reflecting and getting personally involved rather than in the fixed text of the written life story or life book as such, regardless whether it has a narrative form or not. It is only in acts of telling, listening, writing, reading, reflecting and engaging that one learns to get to know the unwritten book of a client or of oneself. Narrative ethics requires that we consider what is written down as nothing more than a side effect of the process of encounter, involvement and relationship between clients, care givers and others. As I have indicated, the text is a temporary anchor point that invites and motivates us to explore new mutual ways of being present to each other, thanks to the acts of telling, listening, writing and reading that have preceded it and will follow it.

Finally, and even more fundamentally, anyone involved in narrative ethics as practised in nursing should keep in mind its limits. We must be conscious that no spoken or written text can fully contain the lived life of others or of ourselves. A veil covers what is unsaid and unsayable. Being able to picture what has not been said would be comparable to hearing grass grow or noticing the heartbeat of the squirrel that flees our approach. We would collapse under the 'roar that lies on the other side of silence' as George Eliot once wrote (Allen, 1993; p. 28). And yet, it is exactly what has not been said, this roar on the other side of silence, that gives a life the gravity and importance that makes it worthwhile to tell and to write about. In the moment of epiphany a glimpse of what has not been said becomes tangible, without allowing itself to be fully understood. The words not said keep each life story open for new impressions, for the unexpected, for what has been promised. It persuades us to respect the pre-narrative mystery of the other.

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