

# How Nurses Can Facilitate Meaning-making and Dialogue



# How Nurses Can Facilitate Meaning-making and Dialogue:

*Reflections on Narrative  
and Photo Stories*

By

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# INTRODUCTION

This book is about narrative/photo stories and their role in identity-making and more generally meaning-making processes. This is looked upon from a hermeneutic-phenomenological point of view as well as from a sociological, psychological and even an evolutionary biological point of view. It considers *how* narrative is told and in *what context*, because beside the narrator there is always a public that ‘receives’ the narrative and responds to it. In health care the public is made up by peers (other patients), relatives and professionals. Among them are nurses, who often have lots of contacts with patients on a 24-hour basis. They are in the position to hear the patient’s story not only while giving care, but also during more informal communication throughout the day. This puts them in the position to use their response to patients in a more conscious way and realise therapeutic aims by exploiting narrative means in a methodological way. How this can be done will be extensively described in this book, not only through a theoretical exposé but also by using case stories. In addition to this pragmatic focus, the book explains how narrative relates to larger concepts such as self-management, shared decision making, recovery and person-centred care, and shows that narrative can be a vehicle to these desired outcomes. A lot of attention will be devoted to visual narratives, especially photo stories and their potential for empowering the patient story, not only in residential settings but also in the community. The book also considers organisational aspects of narrative-oriented health care by introducing a model in which narrative plays an important role. As such, it will allow nurses in the field to make a paradigmatic switch from a perspective dominated by delivery of care to one that is person-centred, recovery-oriented and dialogic in nature.

In this book we use the word ‘narrative’ and ‘story’ alternately, but ‘narrative’ is preferred when we discuss story-telling in a more epistemological or methodological context.

In order to guide you through the book we will sketch an outline here. The first 3 chapters are introductory and very much pragmatically written. Chapter 1 is about the dialogical potential of narrative and the impact the nurse can have on it against a background of person-centred care. Chapter 2 elaborates further on the person-centred paradigm, the relational nature of

narrative and its social functions. As in Chapter 1 the argument is built up from a starting point in a case report. Chapter 3 focuses on the role that narrative plays in creating an internal and external representation of reality and why there is a constant need for updating this internal representation (of which the self-image is a part). Or, in other words: there is a need for a story about oneself and one's relationship with the world that represents one's intentions, goals and values in a credible way. It is postulated in this chapter that constructing and developing a meaningful story may be crucial to the transformation of someone's illness identity and the incorporation of themes of empowerment and agency. In this way narrative is linked up with recovery-oriented nursing in mental health care.

Chapter 4 is about the need in mental health nursing for a conceptual framework that can help nurses to bring about a therapeutic alliance with their patients and maintain it during the time patients are in their care. The conclusion is that narrative and story-telling are the media in a process of emotional bonding in the professional-patient contact that aims as much or even more at dignity than at goal readiness.

Chapter 4 is a bridge to the theory-driven Chapter 5, providing the conceptual framework for that which follows. Chapter 5 contains an epistemological argument of narrative in which much of the earlier chapters is more systematically recapitulated and then linked to a hermeneutic moral model of which the first outlines are drafted. The hermeneutic moral model reflects the therapeutic essence of how nurses can facilitate patients to narrate/tell their lived experience. This can be summed up in the concept of 'enacted narrative'. Chapter 5 can be considered the core of the book.

In the following chapters a number of issues are further explored. Some of them are again illustrated by case studies. In Chapter 6 the issue is the functionality of pathological behaviour as an outcome of the self-regulatory mechanism. We dwell on the dignity of risk-taking and its moral aspects. In Chapter 7, which concerns self-efficacy and social learning, we describe how narrative may become the vehicle for awareness about deeper values, strengths, hopes, and expectations. In Chapter 8 we focus on risk assessment and again on shared decision making, examining how they relate to narrative. In Chapter 9 we link up the exigencies of self-management with motivation and how photo stories can be instrumental in such a context. In Chapter 10 the subject is 'transitions in health and in health care' and we will go into the question how self-management to cope with transitions in health can be best served by advanced nurse practitioners. Meaning making is the crucial factor here and the chapter explores how nurses can facilitate



it. In Chapter 11 the photo story is again the topic of interest as we explore how the therapeutic effect of working with photo stories rests on the triad 'reflection---expression---self-representation', but only where the triad becomes integrated in social interaction and dialogue. In Chapter 12 it is explained why working with photography is called hermeneutic photography and how it is embedded in the philosophy of Ricoeur. The representation of the self in photo stories is further discussed in Chapter 13, as is the contribution of photo stories to more mutuality in the relationship with professionals. How the triad 'reflection---expression---self-representation' in photo stories operates, is demonstrated in Chapter 14. We will demonstrate how patient stories are sometimes 'closed narratives' and that patients may 'frame' the perception of the world around them in terms of that same narrative, so that it becomes repetitive and self-confirming, as expressed in lamentations about oneself. Making photography assignments and sharing the results with therapists and peers may however interrupt this repetitive cycle and reinvigorate the life story by infusing an awareness of vitality. This is also argued in Chapter 15 about hermeneutic photography in a post-conflict country where it may create a context for relational and moral learning. The focus on a 'valued life' will help victims of violence to reorient their lives and find new meaning, enabling them to connect again with values, wishes, and options in life, and prepare them for the first steps to realising personal goals. We will discuss how this widening space for reflection, and the chance to express and represent oneself through images and text (beside sharing them), are aspects of the moral and psychological conditions for a successful recovery from trauma. In Chapter 16 we will claim that this is not only the case for traumatised people but also for patients with severe diseases, like cancer. The act of making photographs is essentially a social event and therefore involves relevant others in the process. The case of Ann in Chapter 16 demonstrates that there is a need for sharing crucial moments in life and having others testify to you being a valuable person, as well as understanding that this belief in who you are must be made concrete and visible. In an appendix to Chapter 16 we postulate that this contributes to more resilience and eventually facilitates the process of recovery from cancer. In Chapter 17 we conclude our tour with details on an organisational model that accommodates self-management, awareness of a valued life and person-centred care.



# CHAPTER ONE

## IMPORTANCE OF THE PATIENT'S NARRATIVE AND DIALOGUE IN HEALTH CARE

A version of this chapter was published as an article in *International Journal of Emergency Mental Health and Human Resilience*, Vol. 19, No. 2, ISSN 1522-4821

### Introduction

There is a growing interest in the central role of the patient's narrative in health care. How patients see themselves and how they assimilate their experiences with illness and recovery in their larger life story becomes more important when we see health as a dynamic process, in which patients are coping with adversities in life, instead of a static state of idealised well-being and absence of disease (Huber et al., 2011). The self-image of a person is to a large degree transitory and determined by narratives about everyday life, especially the meaningful ones about life events (McAdams, 1993; Miller et al., 1990). Our identity is shaped by the concepts that we use to label our experiences in the past and in the present. Personal stories sometimes serve to organise the otherwise raw and overwhelming sensations, disturbing feelings and thoughts that surround difficult life situations. What a person expresses and communicates need not always be 'storied' in linguistic formats. A person can also embody what he goes through or find expressive means other than language to 'tell' his story, for instance with photographs (Sitvast, 2012). The term 'narrative' encompasses all these formats of expression (Sandelowski, 1991). The case of Pieter will demonstrate what this looks like and how health professionals can respond to the narrative in such a way that it furthers and improves mutual understanding.

### The Case

Pieter is a 40 year old man who has been diagnosed with schizophrenia in the past. Today he lives alone in an apartment in the centre of a medium-

sized provincial town in the Netherlands. An outreach worker from the local community mental health centre is in regular contact with him. Pieter, who is of Indonesian heritage, identifies himself as part of the indigenous people of North America. He dresses as one of them and he has transformed his apartment to reflect this heritage and that's why it is adorned with totem poles, indigenous masks, bows and arrows, feathers, etc. He makes these objects himself and names them using native tribal conventions. With all these small works of art there is a story that has been threaded into his self-made mythological world which incorporates his own personal experiences. Wearing the feathered attire at times makes him a colourful figure in the streets of the town where he lives.

Pieter has been an inpatient for many years and is known for a longstanding traumatic history of violent incidents, in which he hurt himself and others (nurses on the ward). His life has now come into a more tranquil phase and six months ago he moved from the hospital to his own apartment. I visit him at his home in my role as his mentor nurse, supporting him in his daily life and maintaining contact with the services. When I ring the bell and he opens the door, I see that I have woken him up from his afternoon nap. After welcoming me he makes me a cup of tea. He cleans the glass carefully before pouring out the tea, which I think is very considerate. I then admire his drawings and Pieter starts telling me about the figures he has depicted. It turns out to be a magical worldview with mythical heroes, spirits, and demons which are interwoven with his own life story. I listen to what he tells me with attention and then answer that it seems he has come upon deeper truths that he is now trying to put into words. I bring up the longing for purity and cleanness in his story and how these seem to be related to the tribal peoples of North America in their intercourse with the environment and the harmony of nature. I suggest he wants that too and that that may be a good reason to tidy up his room and clean it. Pieter agrees and we set about cleaning his house.

### **Narrative Individuation**

How a person sees themselves is to a large degree a function of their interaction with others. When the relationship between people changes then the image that people have of themselves also changes. Someone's identity is not a segregated closed inner world in their head, but something that interplays with social functioning (Polkinghorne, 1998). A person's identity is the condensation of all stories that they tell themselves and others in social interaction(s). Every individual has the need to position himself or herself in the social and cultural room (space) that he/she participates in and

'inhabits'. This appropriation of one's own place is sometimes called 'narrative individuation' (Kunneman, 1995). The individual wants to determine the coordinates of their position here and now. This is done in a narrative way (verbal and non-verbal) and it suggests that 'co-habitants' (the others) of the same social room hear the narrative, respond to it, and can participate in it. The delimiting of one's own place within the social space results from others acknowledging the narrative, but also from others denouncing it or evading it. The individual constructs unremittingly and continuously their own identity in the diversity of many social rooms. In the case of Pieter for instance, we can see how the nurse is shown around in Pieter's house and is invited—as it were—to share the meanings that Pieter gave to his life where identity then becomes co-constructed.

### **Role of the Nurse**

Nurses can help people to lift their life out of the shackles of disease (Grypdonck, 1999). Diseases and disorders, limitations and handicaps, are threats or challenges to a meaningful life story. To be able to help patients to live a life beyond disease and experience life as meaningful, the nurse must acknowledge that the patient's narrative plays a central role in the communication between health care professionals and patients. The patient is a subject with whom the nurse relates to in a subject-subject relationship. This is a core aspect of person-centred care (McCormack et al., 2010): the perspective of the patient, his or her subjectivity, cannot be ignored and nurses should help the patient to voice their own story. Nurses are in a unique position to support patients in expressing their knowledge and experience of the physical and social world they inhabit here-and-now (Benner, 2000). For instance, nurses can name the sorrow as they see it in patients and make it an issue that one can speak about. It is not necessarily rational knowledge already present in the mind but also experience and intuition that can be traced from body language. Sensations and experiences are often strongly influenced by emotions and sensory-motor observations and patterns of coping. People 'live' their story, they 'are' their narrative. The embodiment of experiential knowledge or intuition based on 'events' in the psychosocial domain can be 'read' by nurses. Putting in words what is only implicitly engrained in the body is what proficient nurses are good at. Communication with the patient about their story can be healing. The emotion that is named, especially in the situation when the nurse mirrors a message that the patient before did not (fully) understand or could not face, liberates and opens up new horizons of meaning and sets free new energy (Benner, 2000; Wiltshire, cited in Aranda & Street, 2001).

## Point of Impact

This is the point of impact where nurses connect. The nurse is the interlocutor, listener and audience at the same time, which means that he/she always plays a role in the patient's story. The patient cannot but communicate, even when keeping silent at times. The reactions of the nurse, including a possible non-response, will feed back to the patient. Trying to make sense of the patient story is the first challenge. Sometimes the story is inaccessible at first sight and it might be hard to connect with in an empathetic way, as may be the case with psychotic patients. Yet even then one can read a message in the deep structure of the story that does make sense, because in a psychosis one also borrows meaning from the repertory of collectively shared images in our culture and these are never purely idiosyncratic.

Acknowledging these meanings to exist and validating them as an expression of legitimate needs, wishes, or feelings is of enormous therapeutic importance. How to meet a person's wishes and needs comes next. In Pieter's case the nurse validated Pieter's experience without passing judgement about its reality. He did this by naming a deeper layer of meaning: Pieter's longing for purity, cleanness and harmony. This deeper meaning can be empathetically shared by the nurse while the seemingly psychotic phrasing on the surface appears bizarre or incomprehensible. Pieter felt himself understood and accepted. The nurse found an entry to ground their contact on a shared understanding and to connect with him. On this ground the nurse can, when helpful, suggest alternative turns to the story or stimulate the patient to take up another perspective (Clark & Standard, 1997). For instance in the case where a person imputes the role of victim to himself in the story he tells, the nurse may suggest that a more active role is also possible. The nurse may facilitate this shift in perspective by creating conditions for a social interaction in which the patient experiences how things can be different and in which he/she can have alternative roles. In an arts-based project for instance instigated by Sitvast (2012) people with severe mental illness organised and directed the exhibition of their photographs themselves. They entertained, informed and touched visitors emotionally with their photo stories. For a moment they became actors in their own right and deliverers of an exhibition enjoyed by others instead of being mere consumers of care.

Summarising the roles a nurse can play in a narrative, person-centred approach of care the nurse must:

- Try to understand the essence behind the surface structure of the patient narrative
- Phrase the message and give it back to the person to check whether it is correctly understood
- Validate the narrative's essential message
- Look for common ground and starting-points within the space of the narrative
- Base nursing interventions on this common ground and shared starting-points (preferably in a shared decision-making process).

### **Normative Professionalism**

This dialogical narrative approach has been described in a literature review by Mikhail Bakhtin and was adopted in nursing practice (Bowers & Moore, 1997). Bakhtin assumed that in social interaction there is a constant and continuous interchange and reciprocal influence of consciousness and meaning making (Figure 1.1). The social and psychological entities in the conception of the self that arise from interactions of the person with others have a fluid character, because they are elements of a dialogue with an open end.

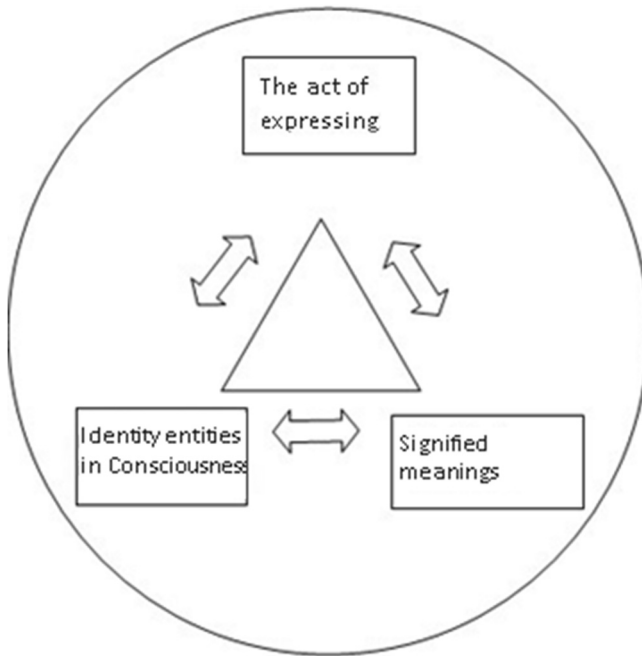
Nursing can also be perceived as a process of social interaction in which the nurse applies communicative strategies to mediate in what illness and handicaps mean for living one's life. This can best be done in an open non-judgmental way of exchanging information where events and experiences are signified within the relationship and not on the basis of a hierarchical difference in knowledge between an expert professional and an 'ignorant' patient. Of course, the expertise of the professional will come in at some point in time, for instance when the patient asks for a definition of their complaints in terms of health and disease (the diagnosis). The professional can draw on the universal (generalised) knowledge of therapeutic interventions, sometimes evidence-based, to meet individual care needs. Doing so he/she will make use of technical medical and nursing jargon, diagnostic concepts, etc. This language often replaces the patient's way of phrasing their complaints and needs. It is what the patient may also want when the professional language legitimises his care needs better than his own formulations. But the other side of the coin is that a gap is created between the professional and the patient narrative which means that the patient can sometimes hardly recognise themselves in a diagnosis and treatment and nursing plan. Of course, with the professionalisation of nursing we now have classifications and standard interventions that have

formed their own jargon. However beneficial this has been for the development of nursing, it does not justify that the patient narrative serves no other aim than being a source of information for the 'real' narrative: the diagnostic description in a nursing or treatment plan. In order to avoid this pitfall we need a normative professionalism as well as an expertise-based professionalism. While the expertise-based professionalism is related to the concept of 'performance', we connect normative professionalism with 'reflectivity' (Widdershoven, 1999; Sevenhuijzen, 1996), 'responsiveness' (Tronto, 1993) and 'presencing' (Baart, 2001; Kal, 2001).

Reflectivity is the ability to see things in a larger context. Professionals often give priority to what must be done and the action needed to solve problems. They run the risk of developing a fixation on interventions, which they can defend very well from their professional expertise, but less from the point of view and context of the patient. The 'why' and 'to-what-aim' questions are sometimes answered from a narrow framework of diagnostic thinking. However, diagnostic reasoning should always be an integral element of a broader clinical reasoning that considers a wide range of psychosocial issues. This is where responsiveness is important. Do we hear what deeper needs and wishes the patient voices with their narrative or do we interpret their expressions too easily as symptomatic and exemplary of the disease or illness? Does our response to the patient connect with their request for help and their life world? This takes a professional who can be *present* as a subject, someone who does not hide behind the mask of their formal professional identity, but who uses their own personal qualities as instruments to connect with the patient in an 'authentic' way. What did that look like in Pieter's case? Here the nurse used a kind of stoic interest (an attitude that was natural to him) in his approach to Pieter. 'Presencing' has also everything to do with how accessible a professional is: the patient must feel that they can approach a professional easily, meaning that an appeal can be made to the professional. With Pieter this could have meant that if there was a conflict with his neighbours the nurse might step in to mediate between Pieter and his environment. This touches on 'performance'.

Performance ('prestatie' in Dutch, stemming from the Latin 'preastare': 1] to excel in something; and 2] making oneself answerable for a person) stands for the capability, the expertise and the courage to act in situations where vulnerable sick people make an appeal to us. They need professionals to act adequately and be trustworthy in their performance. Performance is therefore related more to expertise-based professionalism (Jansen, 2005). Both (normative and expertise-based professionalism) are needed to realise good care.





**Figure 1.1.** Communication circle

## Discussion and Conclusion

Of course, nursing encompasses more than supporting patients in meaning making from experiences related to health and illness. Beside the subjectivity of the experience there is the objectivity of the physical existence and the psychosocial existence (for example if Pieter would have been threatened with eviction for not paying his rent or for making a disturbance). Nursing care consists of the 'technical' procedures and actions to remedy physical needs and psychosocial needs. The narrative here is second to the skilled and trustable performance, even where the technical care almost always carries a meaning to the patient and is embedded in a certain context.

The interchange between the mind and the body is a complex one. We have focused here on the influence in one direction: from diseases and disorders to meaning making by way of narrative. However this path has multiple directions, for example a path that runs from hope based on a newly

found perspective in one's story to recovery, or mitigating the consequences of a disease. This may be the case when hope gives energy, motivates a person to change their lifestyle and where it strengthens their immune system. Hope and a resurgence of vitality may be mediating factors here to find the strength (resilience) to become better—or rather, cope better—with the disease and in this way realise a higher quality of life (Huber et al., 2011). In the case of Pieter, the newly found energy and the focus on purity and cleanness lend him coherence in his identity and his psychological make-up, but how to reconcile this with functioning in a society that tolerates only a certain degree of other-ness remains a challenge and the stake for a continuous dialogue between him and his mentor nurse. How Pieter and his family can achieve a mutual kind of understanding is another matter of concern. The nurse considered organising a so-called open dialogue meeting with everyone involved (Seikkula et al., 2011). He knew that the open dialogue method, which was developed in Finland, has been remarkably successful in striking an alliance between the patient and his social environment, reducing relapse figures as well as re-hospitalisation figures.

## References

- Aranda, S., & A. Street. 2001. From individual to group: use of narratives in a participatory research process. *Journal of Advanced Nursing* 33(6): 791-797.
- Baart, A. 2001. *Een theorie van presentie*. Utrecht: Lemma.
- Benner, P. 2000. The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice. *Nursing Philosophy* 1: 5-19.
- Bowers, R., & K. N. Moore. 1997. Bakhtin, Nursing Narratives and Dialogical Consciousness. *Advances in Nursing Science*, 19(3): 70-77.
- Clark, M., & P. L. Standard. 1997. The caregiving story: How the narrative approach informs caregiving burden. *Issues in Mental Nursing* 18: 87-97.
- Grypdonck, M. 1999. *Het leven boven de ziekte uittillen*. In: Pool, A. en J. Lambregts (red.). *Verpleegkundige zorgverlening aan chronisch zieken*. Utrecht: Lemma, Utrecht.
- Huber, M., Knottnerus, J. A., Green, L., Van der Horst, H., Jadad, A. R., Kromhout, D., et al. 2011. How should we define health? *BMJ* 343: d4163.
- Jansen, M. 2005. *Presentie., & Prestatie. Sleutelbegrippen in een verpleegtheek*. Proefschrift. Utrecht: Universiteit van Humanistiek.
- Kal, D. 2001. *Kwartiermaken. Werken aan ruimte voor mensen met een psychiatrische achtergrond*. Meppel: Boom.

- Kunneman, H. 1995. *Narratieve individualiteit en normatieve professionaliteit*. In Baars, J., & D. Kal (red.). *Het uitzicht van Sisyphus. Maatschappelijke contexten van geestelijke (on)gezondheid*. Wolters-Noordhoff, Groningen, pp. 61-84.
- McAdams, D. P. 1993. *The Stories We Live by. Personal Myths and the Making of the Self*. New York: Guilford Press.
- McCormack, B., & McCance, T. 2010. *Person-centred Nursing. Theory and Practice*. Oxford: Wiley-Blackwell.
- Miller, P. J, Potts, R., Fung, H., Hoogstra, L., Mintz, J. 1990. Narrative practices and the social construction of self in childhood. *American Ethnologist*, 17(2): 292-311.
- Polkinghorne, D.E. 1998. *Narrative Knowing and the Human Sciences*, Albany NY: State University of New York Press.
- Sandelowski, M. 1991. Telling Stories: Narrative approaches in qualitative research. *Journal of Nursing Scholarship* 23(3): 161-166.
- Sevenhuijsen, S. 1996. *Oordelen met zorg: feministische beschouwingen over recht, moraal en politiek*, Amsterdam/Meppel: Boom.
- Seikkula, J., Alakare, B., & Aaltonen, J. 2011. The comprehensive open-dialogue approach (II). Long-term stability of acute psychosis outcomes in advanced community care: The Western Lapland Project. *Psychosis* 3: 192-204.
- Sitvast J. E., & Abma T. A. 2012. The photo-instrument as a Health Care Intervention. *Health Care Analysis* 20: 177-195.
- Widdershoven, G. 1999. Care, cure and interpersonal understanding. *Journal of Advanced Nursing* 29(5): 1163-1169.

# CHAPTER TWO

## NARRATIVE, MEANING MAKING AND CONTEXT-BASED CARE: HOW TO REALISE PERSON-CENTRED CARE

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### **Abstract**

The case study in this chapter illustrates the need for person-centred care. It postulates a central position for narrative in meaning making processes. Three social functions are discerned in the use of narrative. A narrative model deduced from the metaphor of the spinning top is proposed to be used by professionals in their contact with patients. It is argued that there is a need for a context-sensitive, evidence-based practice in which circularity plays an important role. The context is found in the lifeworld, especially social interaction and the life story. Circularity is based on the recognition that both patients and professionals are agents who interact and that there should be reciprocity to some degree in order for a fruitful and therapeutic treatment outcome to be realised.

**Keywords:** Metaphor; Narrative; Person-centred care; Life story; Mental health nursing

### **Introduction**

A disabling mental disease or disorder will often upset the lifeworld of a patient completely. He or she will have to give meaning to the disease or disorder and the consequences it has for daily life. The patient will wonder whether he/she is guilty of bringing on the disease through an unhealthy lifestyle in some way. The patient may feel responsibility for falling short of their own or someone else's expectations. There may be a threat of new

crises with imminent loss of functioning. He or she will need courage and self-confidence to face his/her limitations. There will be mourning over the loss of perspective. Social contacts with relatives may have been changed due to being dependent on care. There may have been a violation of trust because of the patient's actions during a psychiatric crisis. Or, more generally, we see relationships becoming non-reciprocal; the natural flow and give-and-take in a relationship is replaced by a unilateral caring-for attitude. Identifying oneself as a patient, or being identified as one by others, is as entering another world. The role of a patient can be a refuge where someone takes shelter and sometimes it is a place of exile or rather expulsion, enforced by others. The patient commutes between the world where he/she is a patient and the world of healthy and 'normal' people.<sup>1,2</sup> The concept of 'lifeworld' is important. Following Habermas, Kunneman compared the concept of lifeworld with the concept of 'systemworld',<sup>3</sup> distinguishing the intersubjectivity and the communication of norms and values from the communication by way of purpose rationality and formalised codes, as is the case in economic rules and the exercise of rules and laws in hierarchical structures. In health care we have the standardised diagnostic labels and the approach that emphasises the uniqueness of this particular patient. Both are necessary. One cannot function without the other. Whereas 'lifeworld' can stand for a collective phenomenon, in health care it is more often used to address the unique experiences of particular individuals. Hermeneutic phenomenological research into the lifeworld of chronic illness may explore what it means for someone to have rheumatic arthritis for instance,<sup>4</sup> how it influences daily life and affects social relations, but also how one's self-image can be eroded showing how much effort it may take to maintain the integrity of one's identity.

The individuality of modern man is seen as a great asset. It is associated with autonomy and considered to belong to the private domain of a self that is strictly defined and delimited from the world around us. This idea denies that experiencing one's identity always is dialogical by nature. How we experience ourselves is in fact an instantiation of a discourse (conversation) that the individual entertains with himself and others in his environment. It is a discourse that aims at understanding oneself within the interaction with the world around us and is related to the evolutionary necessity to (re-)act adequately upon what comes on our way. We have a need for legitimating our actions.<sup>5,6</sup> People tell stories (be it fully-fledged stories, or anecdotes, puns, etc.) about what they experience and in this way they define their identity. Philosophers such as Ricoeur and MacIntyre claim that stories are necessary to motivate actions and that it takes a community of other people to 'receive' these stories and to respond to them.<sup>7,8</sup> Stories create a unity, lend

coherence to experiences without which life itself would be incomprehensible. They structure our experiences and give direction to life.<sup>9</sup> The degree of exchange between the told story and action in reality (how they influence each other) is a matter of discussion. MacIntyre speaks about “human actions as enacted narratives”.<sup>8</sup> This could be interpreted as deterministic, with people locked up in the script of their life story. Social-constructionist psychology takes a stand here and opposes this idea.<sup>5</sup> A narrative develops as the outcome of interaction between a narrator and his audience. It is all about discourse and conversation.<sup>10,11</sup> This notion matches best with a nursing care in which not the technical routine is at the centre but the inter-human contact (person-centred care).

What is person-centredness? McCormack, one of the leading theorists for person-centredness states that:

Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.<sup>12,13</sup>

Other authors talk about patient-centredness and Patient-Centred Care (PCC), but ‘person-centredness’ is more accurate in its emphasis on personhood and the essential view that the person is more than a patient alone and should be approached as such. This is very much in line with holistic and humanistic nursing (Peplau, Travelbee, Watson and others).

The nurse and the patient are both present as *agents*. In a mutual process they both confirm or deny meanings presented by each of them. They continue this until a story can be constructed at which they reach a consensus; the story is accepted by both of them as ‘true’ and can be the starting point for care actions.<sup>14,15</sup> We then speak of a relational narrative. The concept of a relational narrative can be used to question dominant cultural narratives. More often than not our ideas about relationships, identity, health and illness curtail our potentiality and can be hostile to the full development of our faculties. Dominant cultural notions are easily seen as a matter of course and thus they make it easy for someone who is ill to identify themselves with their disease or disorder. However, humans are not their diseases. Our identities cannot be summed up as being a sufferer from a particular disease. The disease narrative based on symptomatology is one story about a person out of many. The illness and recovery narrative is another and tells the story of how it feels for the person it concerns. Instead

of a person who is a problem someone becomes a person who *has* a health problem. It creates room for a different way of coping with health complaints.<sup>10,16</sup>

## Vignette

### The use of metaphors

Ann is a young woman, diagnosed with a borderline personality disorder. She is an inpatient in a crisis unit of a mental health hospital. She grew up in a Christian-evangelical family. There is a history of emotional neglect. Ann is very demanding towards herself, which reflects the high expectations of her parents. At the same time she lacks self-confidence. She is hypersensitive to criticism from others. This has made her break off from her ballet training. She auto-mutilated herself and was suicidal. Taken in on the emergency ward things seemed to deteriorate. She hardly tolerates her stay on a closed ward. However, she is so afraid of being responsible that she rather avoids taking responsibility for her actions. This situation elicits serious feelings of guilt that she cannot handle. She gets in a downward spiral. When, in a state of dissociation, she starts bumping her head against the wall so hard that severe injury can be expected she is secluded and fixated for short periods of time. Things get worse when she refuses to eat and drink, threatens to set herself on fire, and when the head bumping becomes a regular recurring action. Treatment policy is to stick to upkeeping her autonomy and to take action only as irreversible health risks threaten.

During a day shift I take her out to the garden. In a bed of flowers small plants have come up. I point them out. Then it occurs to me that I can use the metaphor of the small vulnerable shoot of a plant to draw the parallel between the young shoot and her life with the potential of possibilities and growth or development. If she wants to give the shoot a chance to become a flower she will have to water it, but even if she does not, it will grow and flourish under oppression. She is somehow startled, but does not say a word when we return to the ward.

Then there is moment of change, a *turn* in her attitude and behaviour. It started with her announcement that she would like to go to a friend that weekend. "Okay, fine.", I said, "but show us then the coming days here on the ward that you can function without needing us to care for you." Subsequently she lost her cool and started to shout and throw with things. The situation escalated and she ended up in the seclusion room. Yet something went on in her mind. The next day her parents came to visit her. They

withdrew to her room together to pray together and ask God to help their daughter. After an hour or so, during which weeping and moaning was heard coming from her room, she came out. She is tranquil and tells me that she understood that God is with her, that she can handle her life now. The auto-mutilation is over, she assures me. She got power and peace from God. She could not have done that by herself, she says. She was powerless, desperate, weak and sick. We nurses hear her with scepticism. How fast will she fall back again into her symptomatic behaviour? Still, our fear turns out to be groundless, because from that day on Ann succeeds in functioning normally and she does not auto-mutilate herself anymore.

### **Interpretation**

Did God really hear her prayer for help? Or is it the context in which her parents literally went to their knees to pray with her? Did it somehow satisfy her as a form of repentance for her suffering from the emotional neglect in her youth for which she never had been able to blame them explicitly? Could she now at last retreat from her symptomatic behaviour without loss of face because she introduced, as a kind of *Deus ex Machina*, the power and support she received from an almighty God while she herself was little and weak as a sinner and martyr at the same time? She simply could not have hit the new road that would lead her to growth and development on her own. That would have implied that she could have done that much earlier and that she must have played the fool then or did not want it for some reason. She needed a God to embrace the healthy behaviour options we mirrored her with head held high. To do that she used, probably without consciously knowing, a dramatic turn of the story from the theatre. We might say that Ann used a cultural notion here to her own benefit.

### **Narrative as performance**

The way people tell their stories can be studied as a performance, as we have seen with Ann.<sup>17-20</sup> How do people for instance use diction, silences, accents, raising their voice or whispering to underline their story? How do they accompany their story with gestures, mimicry and other expressions of their body (for instance of pain or fear)? Nurses read these signs as part of their daily work and interpret their meaning. Stories are told in order to communicate. With our stories we take up positions as agents/actors in real life. Stories do not happen in a virtual world. How we act and interact is real. Life can be compared with an arena (a narrative cliché) where we, in order to survive, must be credible, thus must have welded our life into a narrative unity and where we use narrative tools as circumstances require.



Our stories may vary widely. Variation reflects the diversity of social functions. Gergen distinguishes three main functions that narrative has: it shows a regressive, stable or a progressive outcome (Table 2.1).<sup>5</sup> Things in life may remain unchanged, reflecting stability. A positive change for the better is also possible. Or life can take a turn for the worse. In our modern society change is seen as a dynamic force and is highly valued in individuals as personal growth. Therefore, people may opt for a narrative

Types of narrative	Outcome of the story	Function in social interaction
Stable	Essential values will remain intact.	Consolidation of relationships.
Progressive	Growth, more and better.	Inspire confidence.
Regressive	Distress and misfortune, disease. Become a victim.	Elicit sympathy, compassion and commitment; exonerate people from having failed in one way or another.

**Table 2.1:** Scheme of different kinds of narrative according to Gergen (1994).

in which they clothe their social relationships with the promise of increasing value: anything that becomes ‘more’ and ‘better’ in future. There are however also stories with a regressive character. They too have a clear function in social interaction between people. Stories of distress and misfortune often call forth sympathy, compassion and engagement in the audience. Someone who recounts how depressive he is, usually does not describe his mental state with the intention of giving some objective picture of how he feels but does so to position himself in terms of interaction with others. Regressive stories can elicit compassion and concern at the same time. They may exonerate the narrator from failure and guilt and put the responsibility elsewhere (attribution). In our culture being mentally ill is a diagnostic label that stands for a whole complex of social functions with which an individual is recognised as belonging to a category of persons to which a whole realm of rules, privileges and obligations or expectations on how to behave applies.

Somatic diseases and mental illness are thus embedded in social and cultural codes, that regulate how others can deal with someone in daily life,

but this may not always be for the better where it corrodes the mutuality and reciprocity in the social contact. Receiving care objectifies you as a patient who deserves an understanding attitude for not fulfilling the expectations of an agent responsible for his/her own action that otherwise would be the case.

### **Narrative model for ill persons**

People feel the need not only to position themselves in a social context, but also in the history of their own lives (life story). There is a fundamental need for experiencing oneself as the same person who you were in the past, have become over the years, and who you are now. Growth and development, but also stagnation and regression are fitted into the life story and sometimes become connecting themes between the different periods in life. The life story must however remain credible when told. The sociologist Goffman used the metaphor 'face' and 'the keeping of face' to denote this fundamental need for maintaining integrity.<sup>21</sup> 'Face' consists of positive qualities that we attribute to ourselves. How can for instance a young woman who suffered from anorexia and who was treated for it for over a year in a specialised clinic, resume her life again and fit her experiences with anorexia into her life story? People will ask her: who are you, what are you engaged in, what have you been doing in life? She asks herself the same questions. As long as she considers the period in which she was treated for anorexia as negative then that period will remain an isolated black chapter in the book of her life. Her life story does not fit with her experiences and therefore these cannot be fully integrated in her life. Dominant stories in our culture, the codes how men and women should behave, and the standard norms for success and failure in society can hinder us to find and live our own authentic autobiographical story. It is therefore important that mental health nurses use a dynamic multi-dimensional model with which (dys-)functioning and how the patient sees themself can be explained integrally and diachronically. Which nursing model comes close to this aim? De Jong connected the self-care model to the patient's self-care needs and activities with the image of a top.<sup>22</sup> The rotating top is a metaphor (Figure 2.1).

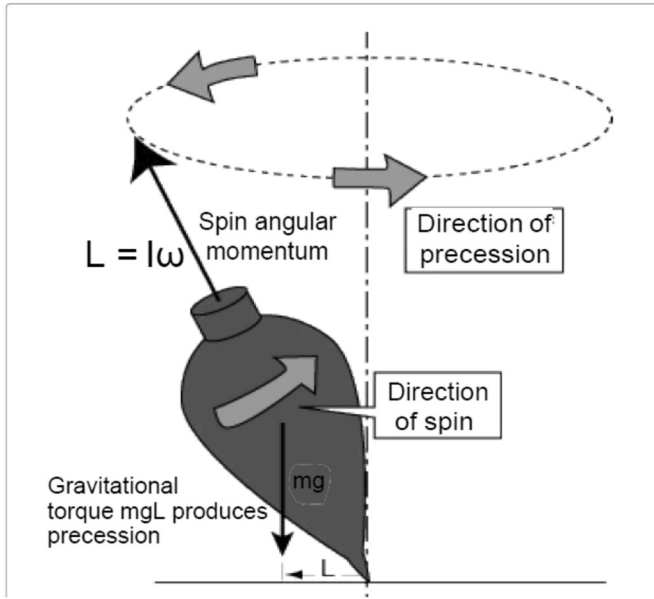


Figure 2.1: The rotating top

People must give a turn to their life (spin the top) and to do that requires a *balance* between the social, somatic and psychic domains of one's life. The metaphor of a top does justice to the dynamic character of the struggle for a meaningful life. A top can turn around quickly or more slowly and may even tumble over. Comparing the way someone goes through life to the course of the top, we can say that development and growth, but also stagnation and regression are akin to the climbing and going down of the top while spinning on a slanting surface, like the spiral in life that for someone can go up or down. With a low orbital velocity someone can fall back into old patterns and routines of behaviour from an earlier stage in life. The orbital velocity is also influenced by the condition of the subsoil (the environment). Obstacles and set-backs can make the top stagger. Illness and emotional damage are factors that influence our course through life, i.e. the movement and direction of the top. The idea of a spiral along which life is enacted is an apt metaphor to help people who have become stuck in a linear or circular story ("everything is a repetition in my life") to realise that the spiral can widen and that we may encounter the same themes in our life, but all along in new variations and with the chance to learn from earlier experiences.<sup>23</sup>

How nurses can use the metaphor of a spinning top and variations to it, as spiralling out of one's limitations and into a repetitive cycle of foredoomed failure, depends on contextual factors and individual aspects of the patient. Timing is important. The metaphor must fit. The connection can be found in key words that may come forward in therapeutic contact and there must be an occasion as in the vignette where the nurse and Ann walked in the garden (the image of a seedling presented itself naturally). Keywords that can trigger the metaphor are: giving a *turn* to life, needing *balance*, life as a repetitive *cycle*, but when you learn from your actions there is a *widening perspective*. Nurses can carry a top with them when they are prepared to use metaphors and take it out during conversations to show what they mean. They will find out quickly enough if the metaphor strikes a note with the patient. When it does not then of course they must not pursue this line of reasoning. It may help nurses to have a stock of metaphors at hand, or rather lying ready at the back of their mind. But it starts with awareness of the power of a metaphor and being keen on finding applications for them in communication.

## Discussion and Conclusion

Nursing that aims at meeting narrative self-care needs will focus on the experience of illness and disorders and how its meaning for the life story and functioning in daily life is interpreted by the patient. The communication and expression of the meaning making process is central.

When there are issues and questions that transcend this focus and which are of a more spiritual or religious nature, then nurses should collaborate with a pastor or a spiritual councillor (or refer the patient to them). The focus for nurses is on the here-and-now and functioning in daily life. However, more often than not health issues have an existential aspect that transcends the sheer practical or pragmatic context. Meaning making is not something that we can leave to the pastor, because it involves the person as a psychosocial being and will influence how effective nursing advice and guidance can be, for instance in lifestyle coaching.<sup>24</sup>

In health care we witness a transition from a supply oriented care to a demand driven care that focuses much more on the specific needs of target patient populations. The development of care pathways to manage a specific disease or clinical condition (and by which is identified at the outset the interventions which are required, what the chronology of care may be, and possibly the expected outcome of the treatment) meets with this call for

person-centred care, but only half way. The approach is instead designed to ease the passage of the patient by coordinating care through the health care system, thereby facilitating personalised care. The Care Programme Approach, as it is also called, is still delivering standardised services that are preferably evidence-based and authorised by care guidelines. What we need however is *context-based* evidence-based care. The recipient of care is a person: a *subject* (agent or actor) and not just an *object* for care. That means that we have to understand a patient's needs in the context of their life world and life story. The care professional needs to be *present* as a whole person (not just performing their role as a functionary), so they are a subject too.<sup>25</sup> Monitoring quality of care that considers care a commodity, based on the idea of a market where consumers of care services and deliverers of care must come to an agreement, is far too narrow-minded. There is no one intervention that is the best. The linear intervention approach must be supplemented by an approach based on context and circularity. Circularity here means that care is a process in which the outcome is not one known beforehand by the input of interventions, because there is a mutual influence of unique persons/subjects (the patient, the care professional and third party persons) and changing contexts. Without this circularity person-centred care would not be possible.

## References

1. Kleinman A. 1988. *The Illness Narratives. Suffering, healing & the human condition*. New York: Basic Books.
2. Frank A. W. 1995. *The Wounded Storyteller. Body, Illness and Ethics*. Chicago/ London: The University of Chicago Press.
3. Kunneman H. 1995. Narratieve individualiteit en normatieve professionaliteit. In: Baars J and Kal D (eds.) *Het uitzicht van Sisyphus. Maatschappelijke contexten van geestelijke (on)gezondheid*, 61-84.
4. Bury M. 1982. Chronic illness as biographical disruption. *Sociol. Health Illn.* 4: 167-182.
5. Gergen K. J. 1994. *Realities and relationships. Soundings in social construction*. Cambridge, Massachusetts/ London: Harvard University Press.
6. Nijhof G. 2000. *Levensverhalen. Over de methode van autobiografisch onderzoek in de sociologie*. Boom: Amsterdam.
7. Ricoeur P. 1977. *The rule of metaphor*. London/New York: Routledge.
8. MacIntyre A. 2001. The virtues, the unity of a human life, and the concept of a tradition. In Hinchman L. P., Hinchman S. K. (Eds.) *Memory, identity, community. The idea of narrative in the human*

- sciences*. Albany: State University of New York Press, pp. 241-264.
9. Widdershoven G. A. M. 1993. The Story of life. Hermeneutic perspectives on the relationship between narrative and life history. In Josselson R., Lieblich A. (eds.) *The narrative study of lives*. Thousand Oaks: Sage Publications, pp. 1-20.
  10. Boeckhorst F. 2001. Narratieve benaderingen in de (psycho)therapie: een richtingwijzer. *Systeemtherapie* 3: 13.
  11. Harden J. 2000. Language, discourse and the chronotope: Applying literary theory to the narratives in health care. *J. Adv. Nurs.* 31: 506-512.
  12. McCormack B., McCance T. 2010. *Person-centred Nursing. Theory and Practice*. Oxford: Wiley-Blackwell.
  13. McCormack B., Dewing J., McCance T. 2011. Developing person-centred care: Addressing contextual challenges through practice development. *Online J. Issues Nurs.* 16: 3.
  14. Gadow S. 1999. Relational narrative: The postmodern turn in nursing ethics. *Sch. Inq. Nurs. Pract.* 13: 57-70.
  15. Sakalys J. A. 2000. The political role of illness narratives. *J. Adv. Nurs.* 31: 1469- 1475.
  16. Roberts G. A. 2000. Narrative and severe mental illness: What place do stories have in an evidence-based world? *Advances in Psychiatric Treatment* 6: 432- 441.
  17. Riessman C. K. 1990. Strategic uses of narrative in the presentation of self and illness: A research note. *Soc. Sci. Med.* 30: 1195-1200.
  18. Wortham S. 2000. Interactional positioning and narrative self-construction. *Narrative Inquiry* 10: 81-110.
  19. Peterson E. E. 2000. Narrative identity in a solo performance: Craig Gingrich-Philbrook's "The First Time". In: *Narrative inquiry* 10: 229-252.
  20. Tappan M. B. 2000. Autobiography, meditated action and the development of moral identity. In: *Narrative inquiry* 10: 81-110.
  21. Goffman E. 1967. *Interaction ritual*. Hammondsworth: Penguin.
  22. Jong de J. H. J. 1983. *Basiselementen voor de verpleegkundige theorie en praktijk*. Amsterdam: Elsevier.
  23. Brockmeier J. 2000. Autobiographical time. *Narrative Inquiry* 10: 51-73.
  24. Sitvast J. 2013. Self-management and representation of reality in photo stories. *ANS Adv. Nurs. Sci.* 36: 336-350.
  25. Baart A. 2004. *Een theorie van de presentie*. Utrecht (The Netherlands): Lemma.