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Photography as a nursing instrument in mental health care

How to use clients' photo stories for recovery

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ABSTRACT

The purpose of this article is to demonstrate how a particular narrative approach in nursing, namely the photo-instrument, can be connected with Ricoeur's hermeneutic philosophy. Ricoeur's concept of mimesis, when supplemented with the concept of performance, is shown relevant for understanding how patients construct and reformulate meaning in illness experiences.

A single case study is presented for a tentative exploration of how the key concepts of mimesis and performance can broaden our understanding of practice. More specifically it concerned the use of photos in a group with psychiatric patients.

INTRODUCTION

Narratives are considered to be an important way by which we can gain insight in patients' subjective experiences. In nursing research narrative research is an emerging, yet relatively new approach¹⁻³. In nursing practice narrative-based approaches are rare. A nursing approach can be considered to be narrative-based as the subjective experiences of patients communicated to the nurse as stories hold a central place which must be reflected in nurses' actions. It is recognized by an increasing number of authors that narratives can be of ethical significance^{2,4-8}. One of the problems with narrative based nursing is the limited interrelation between theory and practice. There are some examples of the development of a narrative theory on the level of nursing praxis⁹⁻¹⁵, but they have not (yet) found wide acceptance. This is in itself remarkable as virtually all nursing practice is based in narrative dialogue between nurses and patients. Newman^{11,12} and Parse^{13,14} for instance developed nursing theories with strong narrative overtones. Newman and Parse both emphasize health as an evolving process of meaning giving to experiences in life. Newman and Parse have set outlines and gave detailed information for a practice methodology that fits a narrative-based nursing.

In line with the work of Parse and Newman we sought to broaden the narrative basis for a nursing praxis by connecting it with the narrative philosophy of Ricoeur¹⁶ supplemented with theoretical notions on performance. We not only adopted Ricoeur for his interpretation of the so-called hermeneutic circle as a model for directing our research as did other nursing researchers^{1, 17-18}, but we also explored whether Ricoeur can be used as a framework for understanding narrative processes within nursing practice itself in terms of hermeneutics. In the Scandinavian tradition of nursing as a caring science it was especially Eriksson who explored Ricoeur's work and adopted his work to understand and make sense of suffering in the context of a 'caring conversation'¹⁹. We follow this approach, but also add something, in that we focus on the role of images and photographs in mediating meaning. The hermeneutics of Ricoeur revolves round the central meaning of narrative in understanding human action. The connection between narrative and action within Ricoeur's work has a pendant in nursing practice where nursing interventions aim at helping patients to cope with their health problems in daily life and thus have an action-oriented scope. The question we therefore pose is: does Ricoeur offer a philosophical framework from which we can derive concepts that help us understand the process of meaning giving in the context of the lives of persons with mental health problems?

We have tried to answer this question by reflecting on experiences from practice and relating them to theoretical concepts which then informed again practice. We followed this cycle from practice to interpretation and back again a number of times until this crystallized into the present state of understanding. This dialogical process between practice and theory finds its reflection in the structure of the article, which is as follows: first we will present the practice from which we departed for reflection. This is the photo-instrument and how it has been performed. Then we will present Ricoeur's theory. Subsequently we'll consider some aspects of his theory. This dialogue with Ricoeur is informed by our experiences from practice. Finally we will return to practice to see how our understanding of it has been enriched in this way.

EXPERIENCES FROM PRACTICE: PHOTO STORIES

We (the article's first author) used to work as a nurse on a ward of a mental health hospital where patients stayed for a long period while recovering from a psychosis or another psychiatric decompensation. We saw how they sometimes wrestled to give meaning to the often traumatic experiences of their illness and how it affected their lives. In working with photographs we found a suitable method to help patients to

reflect on their lives in a dialogue with other patients and with the nurse conducting the photo group. We then noticed how complex the stories that patients told were and also that story-telling was a very dynamic process. But the most important experience was that many patients were very eager to tell their story. We assumed that this story-telling contributed to healing and restoration. This experience prompted us to search for theoretical concepts that would help us to understand better how humans tell stories and thereby give meaning to their life and illness experiences. We then found that the concept of mimesis, especially how it was interpreted by Ricoeur, led us to a fuller comprehension of the practice of the photo-instrument.

The photo-instrument was developed as a narrative nursing practice in 2000²⁰ and tested in mental health care in the following years. We were inspired by many precursors in the social sciences and nursing scholars who showed how photography can be used as an instrument of eliciting detailed information of persons/patients on their life stories.²¹ The intervention's protocol describes the stages that are needed to have patients or clients make photos of their life world. There are 2x8 group sessions. At the start and again halfway the participating patients get a disposable camera and an assignment that tells them what to photograph. After the participants have taken their pictures they are invited to express their feelings and thoughts relating to the pictures (photo-elicitation). This is done in a very structured way and is extended over a number of sessions. In the end the participants select a small number of photos for an exposition. Photo and text are then combined.

We saw how working with photographs launched many participants in the photo group on a course of story-telling in a bumpy way: participants clearly embarked on developing a story that grew out of a more anecdotally reflecting on photographs. We noticed remarkable shifts and changes of perspectives during the process. This was certainly the case with Ellen, whose story of how she gave meaning to her life we will present here. We selected her because her case poignantly demonstrated that a first understanding can differ from more informed readings after connecting it with theoretical concepts from Ricoeur and others.

The story of Ellen: a first reading

Ellen (a pseudonym) has had several psychoses and at the start of the photo group she was only recently discharged from hospital to live on her own again and take care of her two children. She had taken photographs of her own garden to reflect on her situation and on what she had gone through in her

psychoses. In the first sessions of the photo group these photographs illustrated her situation before hospitalisation: living in an apartment in an area with a lot of social problems where she felt harassed by her neighbours. Lacking a feeling of basic security had contributed to her decompensation. One of the photographs showed a view of her garden from her kitchen window. Ellen used this photograph to tell how outraged she was that her neighbours threw their garbage into her garden and that her complaints to local authorities were denied. Instead she was taken into the hospital and her story was seen as a mad (wo)man's litany. Ellen elaborated her point of view in some detail with other photographs. Photographs of a molested telephone booth demonstrated for Ellen that with all our modern means of communication we fail in getting a message across, as in her case her cry for help was not heard. The first series of sessions of the photo group were finished with a photo-exhibition. Ellen selected the photo of her garden to be shown at the exhibition. Then the second series started with a new chance for making pictures. Ellen set about to make new pictures and returned with a completely different set of photographs. Beside pictures of her mother's garden there were now pictures of shadowed lanes and open places in the woods nearby. There was a remarkable shift in the focus she adopted. Instead of further lamenting on her condition she turned her gaze inside. She wondered how her life until now had been and why she couldn't cope with her emotions. Her photographs of the wood and her mother's garden were interpreted in terms of an all encompassing view of her life. Ellen now told us that she was part of the problem and that she had to work on that in order to live her own life again.

Our first understanding of Ellen was that her story reflected a denial of her psychosis that, seemingly unconnected, was followed up by a new story in which she accepted her vulnerability. We did not grasp that these stories could make part of one and the same process until our understanding was enriched by reading Ricoeur.

RICOEUR'S HERMENEUTIC PHILOSOPHY: A FIRST READING

Things happen to us or we make things happen. They unfold in events; have a beginning, a middle and an end. According to Ricoeur this temporal dimension of human acting is reflected in stories and is the result of a process of emplotment¹⁶. With the plot of a story we reformulate our lived experience into a coherent story. Ricoeur claims that the concrete process of emplotment is mediated by mimesis. Mimesis is a

philosophical concept that goes back to the writings of Aristotle and Plato. As interpreted by Ricoeur mimesis is a process of imitation or representation of action and the way events are organized. It is not a passive copying and creating an identical replica (the Platonic interpretation) but an active redescribing or reformulating the world and plotting it into a story (the Aristotelian version).

This is the process we go through as narrator of stories but also as we read or hear stories. We actively assimilate stories and integrate them into our life world. The way a reader understands a story and its plot may very well differ from the intentions of the author. We read the text from our own background and apply it to our own situation.

The creative process of (re)formulating meaning is regulated by metaphors. Using metaphors we understand and experience one kind of thing in terms of another²², for instance when we say that 'football is war'. In a sudden glimpse the mind perceives how meaning can be expressed in a different way. A game of contest becomes a war between enemies. The work of imagination is to endow images to emerging meanings. These images are charged with symbolic associations. 'War' as an image in the example of 'football is war' stands for a complex concept with lots of associations: from the shedding of blood, the sacrifices for a noble cause to the depravities of starvation, exhaustion and terror. According to Ricoeur we derive the image that is evoked by metaphors not from perception but from linguistic processes. There may be a wealth of imagery in narratives but this imagery does not reflect impressions from the senses. The images are sign-images, that is they stand for associated meanings.

According to Ricoeur sensory images have the role of dispersing meaning and suspending the context of reality²³. This roaming about in images stimulates the imagination and sets someone free from restricting and sometimes oppressive realities, and creates space to formulate new meanings. In this way a diffusion of imagination is followed by a focusing and a concentration in concrete narrative. The suspending of reality in narrative time and a certain cherishing of belonging, a being in this world of fiction, is in itself not enough to realize a critical reflection necessary for a creative reformulation of truths. What is needed is distanciation. We have to distance ourselves from the 'lived experience' as something that is self-evident and taken for granted²³. This distanciation starts from a feeling of not being content to 'live' or 're-live' our lives. We then interrupt lived experience in order to signify it, that is to express in symbols what things mean to us. Distanciation is part of the hermeneutic process, the way we comprehend and understand the world we live in. Understanding is the holistic comprehension, like we perceive things as a 'gestalt'. There is however no understanding without explaining how and why things

are the way they are. Explaining things is an objectifying cognitive operation. One has to put the object that is to be observed and explained in front of the observer at a certain distance. Only then we can observe it from different angles and perspectives. Ricoeur acknowledges the importance of a moment of distanciation in the mimetic process when he demands that the narrative will not refer to a local situation only, but to wider contexts as well. These wider contexts can only be observed by distancing ourselves from the immediate experience. According to Ricoeur understanding and explanation are intertwined and cannot be seen in a binary opposition. Explanation is a necessary step in order to reach a better and fuller understanding. While understanding needs the immediate holistic grasping, explanation needs the objectification and the observing of the objectified at a distance. Only then is a critical reflection possible.

In Ricoeur's theory some core-concepts can be identified to explain the processes of mimetic resonance. First there is the reformulation of our lived experience, triggered by distanciation that comes from being not content with the life as it is lived now. In this reformulation the mind operates on metaphors and imagery. They mediate how new meanings come about. Images contribute to the process where they create a free space for associations from memory and imagination. This is the diffusion of meanings followed by a concentration when new meanings condense in the plot of a narrative. Distanciation also plays a role here where understanding and explaining are interchanging cognitive operations. Explaining requires observation of our point of view from different angles and perspectives, drawing in wider contexts as well.

DIALOGUE WITH RICOEUR

Keeping in mind that we strive for broadening our understanding of processes of meaning within the context of nursing praxis we encounter in Ricoeur's work some aspects that we want to give further attention to.

Life world and literary text

Most photo-stories that were told in the context of the photo-instrument portray the patient's daily life. The stories don't focus on grand issues, but on choices and decisions people have to make from day to

day. Only through these issues we catch a glimpse of larger questions of life. How is the ordinary life positioned in the mimetic process according to Ricoeur?

Ricoeur describes the circle of mimesis from life to symbolization as “an extension of meaning, progressive meaning, from the inchoate to the fully determined”²⁴. Although there is a cyclical to-and-fro movement between text and action, there is also an emphasis on emplotment and ‘worlds’ of meaning that leads away from life as it is lived here and now, “Ricoeur seems to assert that life cannot be lived without literature”, stated the historian David Carr in a discussion with Ricoeur²⁴. Ricoeur responded with his answer: “It is then asked if life needs to be understood through literature. I would answer in the affirmative-to a very great extent.”. For Ricoeur emplotment is essentially a literary configuration²⁵. According to Ricoeur real life eludes comprehension of man. That’s why we need the help of fiction to find a model of intelligibility with which we can understand our lives. Life histories suffer from ‘narrative’ incompleteness and are entangled in a dialectic of remembrance and anticipation²⁶. They lack the clear cut closures of beginning and ending that human action in fiction has. Ricoeur seems to suggest that only if life histories are put under the custody of literary narratives that teaches us how to articulate our lives they can acquire sense.

Ricoeur is right about the ‘narrative incompleteness’ of life-stories. It is true that most people don’t have their life-stories ready, waiting to be told or read as is the case in literary fiction. When we compared this with the stories patients told us during sessions of the photo group we found that stories were incomplete, because they were still under construction while being told. In thinking about life-story there has however been a turning away from theorizing about life-story as ‘an already available story’²⁷ to ‘life-story narrating’. True, in the everyday practice of life-story narrating we usually don’t see linear complete whole stories, characterized by plots. Stories are not always structured along logical linear connections. They often have an anecdotal character. Participants of the photo group for instance recounted their reflections on their lives as fragments that refer to specific remembered experiences triggered by the photographs. In their stories there are ruptures, changes of perspective; new connections are made in an ongoing process of construction and reconstruction. However, this gives life-story narrating a flexible character and is rather one of its stronger aspects than, as Ricoeur would have it, a weakness. It is in this process of construction and reconstruction that people find a ‘fit’ to cope with life and with life events such as the onset of illness²⁸⁻²⁹. In doing so they have linguistic resources or repertoires at their disposal of which literary fiction is only one and not the most important. Photo-stories

narrated by participants of the photo groups show that there is a treasure-house of cultural notions embedded in sayings, practical wisdoms, popular songs and humour that people spontaneously and naturally have access to. In the photo-stories, for instance, we repeatedly found the notion of destiny mirrored in the idea that every individual has to follow his own path in life. These notions make part of a kind of common shared canon, a kind of 'folk psychology' in the light of which our actions and intentions become comprehensible³⁰. But at the same time, as Bruner made clear, to assure individuality we focus upon what is exceptional (and therefore, worthy of telling) in our lives. Therefore the story is just then tellable if the story runs counter to expectancy, although it must do so in a way that is culturally comprehensible³⁰.

Performance and meaning

Our experiences with photo group sessions made it clear that the setting in which the photo stories were told was of eminent importance. We found for instance that the acclaim that participants met in telling their stories stimulated them to go further where they otherwise, in a one-to-one interview, may have halted. We wondered how to reflect on this aspect from Ricoeur.

Discourse and conversation analysts claim that by telling stories we present an image of ourselves and of the motives for our actions in such a way that our stories are considered to be credible and that we as persons are held trustworthy³¹. This is what Ricoeur calls the self-constancy in our identity (the *ipse*) that must be proven and reaffirmed over and again. Ricoeur focuses on the reflexive and ethical aspects. Stories are embedded however in a social exchange between 'actors' who use storytelling in the interaction with others. The expressive and communicative aspects therefore are just as important as the meaning-giving aspects per se. One may even speak of a dramaturgical model, of which the sociologist Goffman³²(1967) is a well-known exponent. He describes how social interaction was regulated by all kinds of rules that governed how individuals enacted or performed their part in conversation. The social arena is compared with the stage where actors perform a part. There is, however, one important difference with the theatre. In real life we usually play our part without pretending as if. We are the roles that we play and we do so as convincing as we can. There is a clear relationship between how someone gives meaning to his experiences, the context within this is expressed (performed, enacted) with identity formation processes. We are our narratives. Narratives are multi-layered and can change, even if it may-be subtly, every time when they are being voiced. Most of us have a whole repertory of stories, sometimes at conflict

with each other, all of them telling other aspects of what persons we are. This is what we also found in many photo stories. Participants in the photo group sometimes told different stories. On one moment for instance their stories reflected more dreamlike artistic ambitions, only to be ignored or even discarded the next moment when their stories related more practical down-to-earth wishes.

When we focus on the performance of patients we must acknowledge that their suffering can mute their voice. Suffering alienates the patient from those around him, family, friends and nurses. It may be impossible to express bitter experiences and the unfathomable depth of despair, because people are frightened away from too much suffering³³. Their shrinking from the presence of suffering shames the sufferer. It severs the interpersonal bridge between the sufferer and his social environment and causes feelings of isolation and alienation³⁴. We saw examples of this in photographs that participants did make, but declined from commenting on. The fear of not being heard, the unspeakable nature of the suffering, the fear of causing others suffering or the newness of the experience can stifle one's voice. This disconnection is part of suffering', as Frederiksson and Eriksson reported from their study on narrative understanding⁹. The essence of the struggle of suffering is the conflict between shame and dignity³⁵. It is a struggle to make yourself heard. Only when someone succeeds at having his true self confirmed by others then shame can be overcome.

The question to what degree humans safeguard ethical values at the core of their identity and how they can be held accountable by them, is one that Ricoeur's concept of the *ipse* touches on, but that threatens to be neglected in the narrow context of performance and the necessity to manage the impressions one makes on others. In the context of this article, however, we focused more on the performative aspects and downplayed somewhat (although not altogether) aspects of morality and community. We intend to focus on these aspects in a future article.

Perception and embodiment

Photographs that participants of the photo group made impressed us because of their vividness. They were more often than not related to concrete experiences and to places that actually were the *mise-en-scènes* of individual lives. Images seemed to link up with strong sensory perceptions.

Ricoeur attributes to concrete images a limited role in the process of mimesis, namely that of dispersing imagination. The images become intelligible only through interpretation in language, by which they become imagery. Ricoeur denies the imagery of having strong links with perception. This reduces the image to the role of a vehicle for a linguistic signification. However, we use language to describe images and we use images to grasp meaning of language in a 'Gestalt'. Perception also precedes understanding and can have a freshness and acuteness that communicates itself in 'dense impressions'³⁶. The relevance of 'dense impressions' for nursing is that skilled nurses make use of these impressions when they observe their patients. Before rationally knowing what the matter is they are alert to impressions that flow directly from open and receptive perception. Opposing impression-images to sign-images, as Ricoeur does in '*Time and Narrative*',¹⁶ does no justice to the impact (visual) perception has in the process of signification, which is not limited to the mimetic process of written texts alone.

Considering the relevance of Ricoeur's thinking on narrative for understanding a narrative nursing practice we conclude that the concept of mimesis gives an adequate theoretical explanation of the meaning giving process as such, but also that there are aspects that deserve attention: :

1. The theory puts emphasis one-sidedly on and overestimates the role of literary texts. Ordinary stories told in every day life are disregarded.
2. Communicative aspects of performance and representation in a social context remain underexposed.
3. The focus is on linguistic processes, which leads to an underestimation of the role of perception and embodiment in the process of giving meaning.

Therefore Ricoeur's narrative theory with mimesis as its central key tenet must be supplemented with the concept of performance and representation to bridge the gap between hermeneutics and the communicative setting of nursing.

ELLEN'S PROCESS OF MIMESIS AND PERFORMANCE

In the former section we departed from theoretical concepts to see how they informed and enriched our experiences from practice. With this interpretation of Ricoeur we will now again return to Ellen and see how our understanding of her story can be widened and enriched. By doing so we follow the hermeneutic arch of interpretation and understanding

Ellen's process of mimesis

Ellen set about narrating her life-story. She didn't do this in a linear way. Her story was fragmented. As we saw she initially focused on the vandalism afflicted on her, with her garden as central point of view, but then she reconstructed this image and via a detour of images of the wood she developed another narrative. In narrating her story she borrowed cultural notions from the stock house of folk-psychological tradition. She, for instance, used the popular notion that every individual has to walk his own way in life, to overcome obstacles, pass through dark and light moments, but in the end will find light and hope. This is what she told about photographs of shadowed lanes in the wood where the sun shines through the trees and where there are sunlit spots on the ground (figure 1). She says:

“There is a clear path where the light shines on. [...] The challenge is to become better and to continue life without fear [and] in a safe place to live. I want to take the fear out of myself by having time pass by and do its job and by acceptance. Medicine helps me to accept myself, but also talking with friends”.

According to Ricoeur images then are no longer confined to a concrete basis in impressions from senses, but have become mental constructs. Lanes in the wood are transformed into a path of life. The image has become imagery. At the same time, however, it becomes clear that Ellen's story remains firmly grounded in the life she lives here and now. Although she uses the garden as a symbol it still remains an actual place where she felt threatened by her neighbours. The woods she had photographed were the playgrounds of her childhood and a place where she still used to come. Ellen employed the images of the wood for a metaphoric account of her life story. However, the

photographs she uses have such strong impact because of their perceptual density. The lanes leading through the wood are interwoven with her history and her actual life. The dark and light, the open and enclosed spaces in the wood are physical sensations for Ellen, not just symbolic imagery. It's exactly the grounding of the photographs in local contexts and strong sensorial experiences that lend Ellen's narrative such a powerful appeal.

The way how Ellen constructed her narrative from the images evoked by the photographs, illustrates the process of concentration and diffusion in the context of the photo-group. Out of the whole set Ellen was asked to select three photographs that were the most meaningful to her, thereby inviting her to foreground certain themes, prioritize interpretations and pattern her narrative. From the fragmented interpretations of the photographs we saw above (diffusion of meaning) she emplotted a new narrative in the end (condensation):

“With the three photographs I outline symbolically where I stand in life and what it did to me. How I felt, still feel and how I will feel. What it meant to me and how it resulted in my present views [..] The challenge to face life and go for it notwithstanding obstacles, emotional black holes.”

Ellen's performance

In the first sessions Ellen told her story as a monologue without allowing others to suggest different perspectives, as if she seized the opportunity now she had the platform and didn't tolerate interruptions. She made the impression of eagerly wanting to tell her story. She may not have had this opportunity that much before, without caregivers interpreting it in terms of disease symptoms or psychosocial malfunctioning. May-be this is what she referred to when she commented (in an agitated voice):

“My therapist told me that I should not engage myself in thinking about the future but that's what I actually do in the photo-group”

Earlier experiences with professionals reducing her story to her illness may partly explain how she initially performed her story. The integrity of her story had to be defended against alternative interpretations, especially that of psychiatry. That's why her story was foreclosed and presented as a monologue.

After having experienced that she had been able to tell her story without disqualifications and that it had been heard and 'received', by the others in the photo-group, only then Ellen could allow other perspectives and develop a new narrative. This is reflected in her presentation. Initially Ellen was emotionally uptight with rage and indignation; she did not show these feelings and presented her story as if it were an observation by someone else. Later on Ellen opens up. Her story becomes embodied, expressing her feelings and emotions. This way of telling is as much part of her story, as its verbal contents. In the case of Ellen storytelling is not just a matter of telling alone, but also of presentation and enactment. Ellen's narrative becomes embodied where at first it was literally 'stifled' in a pose of constraint and apparent non-commitment. Listeners, including the nurse therapist, could 'read' Ellen's story by interpreting the transitions in her body language.

How Ellen develops her narrative touches upon a crucial point, namely that the act of telling the story is set in a performance. By telling her story Ellen legitimized to other persons choices she had made; her story justified her intentions. The initial representation Ellen gives is of a woman claiming her right to be left in peace and enjoy her rest. She presents herself as a victim from vandalism and she demands recognition for that. In the second round of the photo group sessions there is a shift; Ellen starts to search how to make sense of her illness story in the context of her life-story. We can thus discern a dialogue developing on two levels: an external dialogue with an audience (her fellow photographers in the group but beyond them her psychologist, nurse-therapist and maybe in even wider circles: council authorities) and an internal dialogue with herself. These are the dialogue-settings in which her performance takes place.

Ellen can be seen as a person struggling to find meaning in her life in the midst of suffering. Her performance takes on the form of a 'drama' with three acts⁹: (1) confirmation of suffering, (2) being in suffering and (3) becoming in suffering. The confirmation is what she finds when others recognize her story. 'Being in suffering' means for Ellen that she can take her time for working out her fragmented story in a

more coherent, meaningful narrative that in the end becomes integrated in her life history. During the third act of 'becoming in suffering' Ellen reconciles herself with life again. She finds a new perspective and formulates her hope for a better future, based on a realistic estimation that she herself creates the obstacles that stand in the way. From being a victim of the situation of suffering she comes to recognize the conditions for recovery. The playing with images of the wood stimulated Ellen to begin an internal dialogue, to reconstruct her experiences, to find new meanings, and this contributed to raising her hope. It has been evidenced that this meaning giving process itself leads to a better mental and physical health, for example, in research on the relationship between positive thinking and the response of the immunesystem³⁷.

Re-reading Ellen's photo stories

We started with a first reading and understanding of Ellen' story that left unexplained her change of perspective during the sessions of the photo group. After being informed by the theoretical concepts of mimesis and performance our comprehension was broadened and we understood better how, in the context of the photo-instrument, Ellen found sense in what illness did to her life-story. We saw how Ellen retold her experiences and found a new perspective. It became clear that she could only distanciate herself from the impact of the painful confrontation with her social environment after 'playing around' with images of the garden and the wood. We have shown how these images mediate the mimetic process through a perceptual density that lends her narrative strong appeal. With her photographic essay Ellen started to review her life story. Ellen addressed not only her social environment with her photo-story, she also entered a dialogue with herself. These are aspects of the process of performance. Performance gives her story a

sense of acuity and urgency, because Ellen presents herself as accountable for her own life.

DISCUSSION

What makes the photo-instrument an element of nursing practice? What is its legitimacy as a nursing approach? Nursing has been described as helping patients with problems in daily life caused by and coming from diseases, disorders or the process of dying. The focus of nursing is on helping patients with actual or potential reactions to health problems and/or existential problems related to them³⁸. The photo-instrument does help patients to recontextualize their illness in their lives and to integrate illness experiences within their life-stories. Although a patient's expression is not always understood by the patient or others as suffering it is nevertheless of eminent importance that a person expresses and symbolises her inner reality³³ and doing so put suffering into words before it can be expressed³⁵. This can be seen as a prerequisite for overcoming feelings of shame and restoring dignity. Where a person is not yet able to verbally symbolise her inner reality and experiences with suffering, images can mediate to give birth to language. Younger³³(1995) speaks of the midwifery function of nurses to help the suffering person to articulate her story. The photographic images come to the nurse's assistance in fulfilling this task. Nurses working in lines with Parse's theory will recognize this when they engage in a dialogue with a person: "Languaging' is from the first principles of human becoming¹,[...], and refers to ways of signifying valued images through speaking [..]"³⁹.

It is the nurse's ability to be genuinely present, in the deepest sense of connecting with someone as one human being with another human being, that grounds a healing relation. Restoring the interpersonal bridge, that was severed by suffering and feelings of shame it evoked, is a condition for human becoming and photographs mediate this restoration.

¹ 'human becoming': refers to Parse's assumption that humans are mysteries unfolding in an ever-evolving process of emergence from a human-universe interrelationship. Humans relate with the universe in rhythmically paradoxical patterns in which the human freely chooses meaning in situations and bears responsibility for decisions⁴². 'Health' relates to the experience of humans of living patterns of personal value priorities.

Being truly present is also the basic art underlying the entire methodology of Parse.⁴⁰ As Parse claims “*it’s a special way of being with others that recognizes the other’s value priorities as paramount... True presence is an invitation for person or family to explore the depth of ideas, issues, or events as they choose*”⁴¹ The photo-instrument has taken this invitation at heart.

CONCLUSIONS

Ricoeur sees meaning making in terms of narrative and emplotment. Although Ricoeur recognizes an intrinsic relation between action, the lived experience and its emplotment in stories, he regards this process primarily as textual, rather than performative. In the photo-instrument, the emphasis is on situatedness and corporality of narratives. Our experiences with patients in the photo group show that the intricacies and actuality of life histories can be seen as motors in the meaning giving process. Ricoeur’s theory can be married with concepts of performance and embodiment to realize an enriched understanding of the photo-instrument and link mimesis even stronger to stories from daily life. To this purpose we found in sociolinguistics the concepts of representation, performance and enactment with which we can describe the social function of narrative in the dialogue of an individual with others. In this way we arrive at a broadened understanding of the process of meaning giving in the context of the lives of persons with mental health problems.

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Chapter 3: Façades of Suffering: Clients' Photo stories About Mental Illness

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Abstract

In this article photo stories are examined that were the result of working with photography as a therapeutic instrument dealing with suffering in mental healthcare settings. The purpose is to describe the role of façades in the process of suffering and acceptance. Clients took photographs, talked about them in group meetings and exhibited them to a broader audience. Their photo stories were analysed using a mixed methods model. Data from two narrative approaches (semiotics and hermeneutics) were compared with information from other informants and official records to find discrepancies between the photo story and the real life context. While façades are usually perceived as an obstacle for personal growth, the visual narratives revealed that façades can function as an alternative to common acceptance strategies, such as facing one's losses and reconciliation. Façades can create a distance between the person and the suffering. We conclude that visual narratives can reveal and foster agency in clients.

Keywords

Façade; visual narrative; stories; storytelling; chronic/mental illness; suffering; acceptance; stigma.

Living with chronic illness impacts daily life and the experience of self (Charmaz, 1991; Riessman, 1990; Williams, 2001). The impact of severe mental illness is often enormous (Hinshaw, 2007); the illness disrupts the life story, and necessitates an evaluation of one's identity. Suffering results to the extent one becomes aware of the losses caused by the

illness. The effects related to the symptoms of mental conditions themselves may be compounded by the effects of stigmatization (Hinshaw, 2007; Corrigan et al, 2002). Persons with a mental disorder often have experiences of rejection and stigmatization (Wright et al, 2000). This can lead to coping strategies of secrecy and social withdrawal (Hinshaw, 2007; Corrigan, 1998), or energize persons into anger about stigmatization (Corrigan, 2002), whereas others seem indifferent to the impact of stigma altogether. Little is known about how a person with mental illness experiences life. In this study we tried to get more understanding about how psychiatric clients endow meaning to their experiences and how they represent themselves. The study is based on photo stories made by selected mental health clients who participated in photography groups. These photography groups were guided by the principles of hermeneutic photography. Hermeneutic photography uses photographs to explore possible meanings rather than to depict an objective representation of reality (Hagedorn, 1996).

In this article we focus on how psychiatric clients, in the context of the photography groups, give meaning to their broken lives and suffering and how facades play a role in their visual narratives. The purpose of this article is to describe the role of façades in the process of suffering and acceptance.

CONCEPTUAL FRAMEWORK

Suffering

Suffering from a mental illness can be a painful struggle, because what we desire or long for is often beyond our reach, e.g. being free from severe mental illness. Realizing that one cannot just wish mental illness away can lead to the feeling that mental illness must be endured. One undergoes suffering rather than acting upon it (Fredriksson & Eriksson, 2001). One can be either “sufferer” or “agent”(Ricoeur, 1992). “Sufferers” are those affected by processes in their life story. “Agents”, however, initiate these processes. Achieving an active relationship with suffering, in which one reshapes feelings of fear and anxiety, restores agency (Eriksson, 2006).

A progressive development in suffering goes from being determined by suffering (*have* suffering) to “owning” it, but not yet acknowledging it (*be* in suffering), to confronting and assimilating it (*become* in suffering).

Façades

When people tell stories to account for disturbing events in their lives, such as the onset and progression of mental illness, they sometimes “hide” from their suffering; not mentioning it or not giving it due attention. We speak of “façades” when someone’s suffering becomes invisible. Hiding from suffering is often seen as problematic, because it is assumed that personal growth and development take place on the basis of acceptance of suffering (Fredriksson & Eriksson, 2001). Acting as an agent presupposes that someone faces his suffering, instead of hiding from it behind facades. Fredriksson and Lindström (2002) found that psychiatric clients used façades to hide their suffering from themselves and their social environment. The four façades they discerned are:

1. the alone and strong (feigning strength)
2. being a victim
3. making oneself invisible through adaptation
4. resignation

The suffering that must be concealed from the sufferer behind these facades consists of: feelings of fear,

evilness, hatred, revenge, rage and shame. Shame, in particular, may be so intense that avoidance strategies are used as defence mechanisms against overwhelming negative feelings (Nathanson, 1992). Also, cases have been identified in which façades were de-masked by the storytellers and they themselves became part of a heroic story (Fredriksson & Lindström, 2002). In these cases, the story begins with the denial and concealing of suffering and ends with the acceptance and confirmation of it (Lindholm & Eriksson, 1993).

In other cases people may hold on to facades in order protect themselves from experiencing too much pain or suffering. If people battle against illness and the suffering it causes, “they do so for control of the defining images of self, for control over their bodies, and sometimes for control over death” (Charmaz, 1991, p. 259). This implies that one actively defends the image of self. The struggle is how to preserve self-respect. Self-respect is sustained by having control over situations and by being able to make independent choices in some domains of life, if not in all (Charmaz, 1991). These choices can hold suffering at bay, ignore or externalize it. Similarly, a façade can be freely adopted and offer an alternative to assimilating (internalizing) suffering.

METHODS

Setting

Our research studies and follows nine photography groups in three mental health institutions in the Netherlands. The aim of forming the groups was to help clients in their process of assigning meaning to their illness and experience of suffering. Comparable therapeutic interventions have been used elsewhere (Fleming et al, 2009; Hagedorn, 1996; Frith & Harcourt, 2007; Keller et al, 2008; Wang & Burris, 1997; Weiser, 1993). Participants were invited to endow meaning to pictures made with a disposable camera. Nurses facilitated the process of elicitation among participants (see Sitvast, Abma & Widdershoven, 2008). Elicitation means that a researcher or a therapist invites the photographers to tell what the photograph means to them. The photography groups followed a protocol developed and tested by the first author in an earlier phase of the study (Bouhuis, Middelhoven, Schoneveld & Sitvast, 2003). Each photo group passes through two rounds of 8 sessions. Both rounds are concluded with an exhibition in which the photo stories are shown to others. The first round focuses on what participants consider as valuable or dear to them. The second round focuses on the formulation and visualization of a wish or goal that participants would like to realize in the near future.

Settings included a (medium) long-term in-patient ward in a psychiatric hospital, a daytime treatment centre and three sheltered group homes. During 2005-2007 nine photography

groups were organized (in total 42 participants). The criteria for inclusion in the study were that participants were recovering from a psychiatric crisis and that they were not severely impaired by psychiatric symptoms at the time of their participation in the photography groups.

Design

As we wanted to gain an understanding of the role of facades we needed to be able to compare the meanings embedded in the photo stories with the real life context of the clients. We therefore adopted a mixed methods design in which different qualitative research methods were used for the purpose of triangulation and complementarity. By triangulation we sought convergence and corroboration of results from different methods. Complementarity served elaboration, enhancement, illustration and clarification of the results from one method with results from the other method) (Onwuegbuzie & Teddlie, 2003; Greene & Caracelli, 2003). In order to reconstruct the meanings embedded in the photo stories two narrative traditions were integrated. To reconstruct the meanings in the photos (the visual image) a semiotic approach was followed (Riessman, 2008). Semiotics approaches meanings as sign systems; visual images are signs that can take on arbitrary meanings, depending on context (Emmison & Smith, 2000). In order to interpret the meanings in the clients' stories of the photos we used hermeneutics. Hermeneutics approaches meanings as intersubjective understandings (Hagedorn, 1996). Recently, many more examples of hermeneutic photography can be found (Radley & Taylor, 2003; Keller et al., 2008; Frith & Harcourt, 2007). The integration of these two narrative approaches helped to unravel various layers of meanings in the photo stories. A client might, for example, not reflect on the meaning of the split tree on a photo (hermeneutic analysis), while a semiotic analysis might indicate that such an image refers to a broken life.

Yet, as we were interested in the role of facades it was necessary to relate the meanings in the photo stories to the real life context of the client. In order to gain such factual information additional data were collected. Participant observation of the photo groups helped to observe the condition of the client :their verbal and cognitive skills and physical wellbeing. In addition

interviews were conducted with clients after the intervention. Also interviews were held with the nurses leading the photo groups to hear their view on the wellbeing and improvements of the clients. Official records in the form of observation forms and evaluation forms further helped to compare the story of the client with factual data. Inconsistencies between the photo story and the factual data on the life world context helped to illuminate facades. For example, a client may have high ambitions wishing to buy a Ferrari and have a bungalow, but reality might be such that a person is still hospitalized. This cross checking between data aimed not to invalidate the clients' photo story, but to discover discrepancies between the story, and what the story covered up, and why such facades were used and functional for the client. A photo story of a client might factually not be true, but what was of interest to us was that it was true for the client at that moment.

Data collection

Data consisted of photographs taken by participants and the stories that were told about them in the group sessions. Participants made up to 50 photos, but eventually selected a total of seven photographs for public exhibition: three from the first round and four photos for the second round of the photo group sessions. These photographs were the focal point of the participants' stories. Together they formed the photo stories in a primary dataset. The researcher attended all the nine photo groups and made field notes of these participant observations. Nurses conducting the photography groups filled in an observation form to provide contextual information, for instance, on how the photo stories were received by a public. Triangulation of data was also achieved by using evaluation forms and material from a limited number of interviews with nurses conducting the photography groups and with clients. The interviews were written out verbatim. Together with the observational data the interview data formed a secondary dataset. The multiple use of diverse data sets was found in comparable studies (Riessman, 2008).

Analysis

The analysis of the photographs was based on semiotics (Van Leeuwen & Jewitt, 2001). First we analyzed the content in terms of perspective, focus, tone, setting and themes. Then the symbolic meaning, was unravelled looking at the images to which the photos refer (Barthes, cited by Emmison, 2000). The symbolism was understood in relation to its context, which, in turn, provided information on the function it serves for the participant.

The semiotic analysis was integrated with a hermeneutic analysis. The hermeneutic analysis focused on the verbal narrative accompanying the photographs. On this level we analysed what the photographer himself told about the photographs; what meaning was endowed to the photos within the intersubjective context of the photo group. Combining the verbal text with the images we investigated how participants constructed their narrative in terms of perspective, character and plot development and the use of metaphors. We analysed how this narrative related to its explicit message and/or hidden functions.

In order to determine this relationship we also depended on context information drawn from our observations of clients' performance in the photography groups and their comments and responses that were not integrated in the story. In addition to the message of the narrator we thus identified hidden meanings. Façades within narratives may cover up private aspects of life, secrets, even unspeakable or illegal things (Bach, 2007; Riessman, 2008). We deliberately searched for tensions between what was expressed and these hidden meanings. In this way a dataset was constructed for individual cases (compare: Bach, 2007). The next step was to relate the dataset with theoretical notions on suffering and façades to find a possible meta-narrative that enabled us better to see the process of meaning. Findings were again tested against data in primary datasets.

Quality Criteria

As we wanted to find discrepancies between the story told and the life context, and what and why the narrator wanted to cover up certain facts of life and suffering (the pragmatic

function of the photo story) we consider our understanding as being inherently co-constructed with the narrators (Plummer, 2001). Recognizing our own positionality and subjectivity we therefore treated our analysis as a situated interpretation (Josselson, 2006).

Following a hermeneutic perspective we used the notion of “credibility” (Lincoln & Guba, 1985) to ensure the validity of our study. Credibility was achieved by “prolonged engagement.” We engaged in all sessions of the nine photo groups and carried out “persistent observation” during every session. Procedures to ensure credibility also included a member checking of our interpretations with the research subjects. In the member checking we put before them our interpretation of what the images were about, what stories they were part of and whether there were layers of meaning that we assumed to be present in a specific photo-stories. As far the third aspect (the added layers of meaning) is concerned, our dataset is a composed text including theoretical notions on suffering and facades. Its nature made sharing it with participants difficult and not always possible, as the level of education of the participants varied greatly. For member check we therefore rephrased interpretations in terms familiar to the participants. From an interpretive perspective trustworthy interpretations are important to reach internal validity. Member checks help to validate the person’s reality; whether it is understood well; not whether the story is true.

In order to further deepen the surface of the tale being told (visualized in photos), to reveal what remained hidden and unspoken, we took an outsider and realist position, using theoretical insights to bring these aspects to the surface. These conceptualizations enabled us to transcend the limit of what was being told/visualized. The type of validity we speak of here is the so-called explanatory (or theoretical) validity (Maxwell & Loomis, 2003). Theoretical validity concerns the validity of claims about causal processes and relationships. In the case of our study this can be read as: how valid are our interpretations of the processes (for instance in case of façades) with which patients give meaning to their suffering? This kind of internal validity refers to the degree to which a theoretical explanation developed by the researcher fits the data. The strategies we adopted for obtaining theoretical validity are: reflexivity in an re-

iterant process of discussion between first, second and third author, peer review, negative case analysis and theoretical sensitivity (see also Strauss & Corbin, 1998).

The study was executed in accordance with the norms and regulations under Dutch legislation on medical research (the WMO-Law) and was approved by the appropriate Medical-Ethical Board. A proper informed-consent procedure was part of the research protocol.

FINDINGS

In this study we focussed on how psychiatric clients give meaning to their broken lives and suffering (1) and how facades play a role in their visual narratives (2). We will follow these two strands of analysis in the presentation of our findings. First, we will give an overall picture of all cases, then we will select cases for a more in-depth description and we will end with an integration of findings in which suffering and façades are related to each other.

Broken lives and suffering

People can pass through stages of suffering. They can *have* suffering, *be* in suffering or *become* in suffering (Eriksson, 2006). To *have* suffering implies that the person will not acknowledge his suffering and will flee from it, trying to explain it away. To *be* in suffering implies that a person often experiences restlessness and may try to alleviate his suffering through the satisfaction of direct needs. When someone *becomes* in suffering someone engages in a struggle between good and evil, hope and hopelessness, between life and death. Passing through this struggle the person may continue towards a higher awareness and greater spiritual strength (Eriksson, 2006).

In our study (N=42) we found that in making their photo-stories twenty-seven participants mentioned their illness and experiences explicitly and reflected on them. They can be said to *be* in suffering or even to *become* in suffering. This leaves us fifteen participants who did not mention their illness experiences explicitly or only did so very briefly in their photo

stories, but who focussed on other aspects of their lives. As the assignment for making photographs was about values and what one held dear we cannot automatically say that all fifteen clients *have* suffering, meaning that they do not experience their suffering as being part of their lives and instead feel driven and directed by external circumstances (Eriksson, 2006). Carl, like all names a pseudonym, for instance, told how he had taken up bicycling again and how he loved it. There was no explicit mentioning of the hardships of the psychosis he had gone through, although he certainly acknowledged it on other moments than when preparing his photo story. For some other clients it was different. They also did not mention their illness experiences or only as a passing remark, but at the same time we then knew from other data (participant observation, observation by the nurse conducting the photo group) that these clients fled from 'owning' their suffering. They can be said to *have* suffering. An example of this we will see in the case study of Benny in the next paragraph.

Let's return to the larger group of clients who did mention their experiences with illness. In this group we found ample examples of *being* in suffering. Judith, for instance, photographed herself with her arms raised to heaven. She told us that she wondered how she could ever become the old Judith again. She *is* in suffering, experiencing increased anxiety and seeking more harmony in her life. Yet she seems not ready to go beyond this struggle and find new meanings as ultimately happens in the phase of *becoming* in suffering. Susan, however, who participated in the same photo group, knew that she would never see her health restored to how it was in former times, when she was in her glory as a competitive swimmer. Yet she photographed her preparations for a holiday trip to a Caribbean island where she hoped to go and swim with dolphins. In this way she connected future with past experiences and reflected on them. Another example is William who, after several sessions, openly admitted to having an alcohol addiction. Talking about his experiences with mental illness relieved the pain of isolation and alienation caused by feelings of shame. It helped him to make him aware of his struggle against his addiction that he felt as a struggle between good and evil, hope and

hopelessness. Fighting this struggle he won back the respect of his son and in this way he found a new meaning in his suffering.

Façades

Many participants evaluated their lives and explicitly mentioned illness experiences. The evaluative direction of their photo stories could be anything from optimistic hopes for the future to not knowing what turn their lives would take, expectations of more stable conditions or outright misgivings about the future. At the same time this did not say much about the use of façades. Sometimes façades were used in a story where its narrator in some way avoided a direct confrontation with his/her suffering, but then came to realize its true nature and used the insight for re-directing the plot of the story. In these cases the façade that has been overcome can be a part of a progressive turn in a story plot. Ellen, for instance, at first clinged to her idea that external conditions were the cause of her pain and suffering, then realized that her problems were caused by her own psycho-social functioning. She imagined that she would come out of her struggle (dark period in her life) and be happy again. Ellen put the façade aside and developed another way of coping with suffering (Sitvast et.al., 2008).

Overall (N=42) we found a total of 15 cases, in which we could identify a façade. Out of these fifteen façades five dissolved where the story was further developed, thus leaving ten stories in which the façade remained intact. Some of these stories were analysed as a façade with which the participant shielded off painful feelings. Benny, for instance, presented himself with photographs of a glamorous life. He knew that he would be hospitalised for still some time and had to survive on a small living allowance, but claimed that in the end he would overcome his problems and live in luxury. In some other cases the storytellers neither ignored nor denied suffering, but had chosen not to make it the subject of their story. These stories displayed a retreat from the struggle against one's suffering in order to find a temporary respite. Julia, for instance, focused on photographs of her small family: her daughter and her dog. She mentioned her loneliness and her despair, but chose not to address this in her photo-story. Other stories that

also had stability as ultimate outcome could be sometimes characterized as ‘They lived happily ever after’, with no clear linkage to suffering whatsoever.

Strauss (1989) describes how patients recovering from a psychiatric decompensation go through a period in which they do not take up new challenges and stay within the limited domains of their lives: the so-called “wood shedding” phase. This also seems to be the case here. Suffering is often so intense and prolonged that patients need a temporary escape. In the photo narratives that function as a façade participants may tell a story about an ordinary and possible wish. Underlying disturbances cannot be included and articulated since these are too painful. The story functions as an anchor in a sea of turmoil. It helps clients to retain self-respect and not to be overwhelmed by the experiences with their illness.

Three cases

Three of the fifteen cases, in which we identified a façade, are presented here. First, we will describe the photo story of Pieter, that shows a progressive development and a protagonist with a strong need for control. This case contained a clear turning point, and illuminates how the confrontation with reality may help the process of recovery. As such this story illustrates the assumption in emerging theories on façades that we presented earlier on, namely that façades need to be surpassed to overcome suffering. The second and third case, however, function as negative cases to challenge this general insight. The second case of Judith has an undetermined ending and presents a façade which became apparent when confronting the story with the life context. The third case of Tanja, at first sight, seems to be a story with a happy ending, but after a closer look appears to be too optimistic. The three cases represent different ways in which clients handle suffering in their storytelling.

Case 1: Pieter's photo story

Pieter is a 29-year old man, hospitalised. He suffers from paranoid schizophrenia. He has no job, lives alone and does not know many other people.

Semiotic analysis: One of the photographs Pieter selected for the exhibition is of a wooded area. Pieter likens his lack of openness and impenetrability to the dense wood in

the photograph: "That's me." Looking for a reason for his lack of openness, he commented to his photograph of an old mouldered elm, ravaged by a storm: "The tree used to be big and steadfast. Now it is sick and mouldered. It has been smashed to bits. That's what a psychosis and schizophrenia does to you."

INSERT FIGURE 1

In the second series of photo group sessions, Pieter elaborated on the theme of hope. A photograph of himself sitting on a fence portrayed him overlooking a meadow. The image symbolizes space and openness. He explains: "Tranquillity and freedom, that is what I think of when I sit on a fence in a natural environment and enjoy the here-and-now."

INSERT FIGURE 2

The second photograph was taken in his room at the hospital and shows a book that has been put in the window. The book is called: "Catastrophobia. The truth behind changes of the earth in the Era of Light". This book symbolizes his fears. Pieter: "The obstacle preventing me from realizing my goals is the secret government. Through manipulation and creation of fear they want to spread their influence. But fear is only in the mind and without it they don't have power over you". A third photograph of caregivers and his doctor shows Pieter in the hospital setting reflecting on the support he receives from them.

INSERT FIGURE 3

Hermeneutic analysis: The second photograph marks a turning-point in his photo story. Pieter switches to more direct reflection and becomes more concrete and specific as to the content of his feelings and thoughts. There is a subtle development in the plot that shows increasing agency of the narrator. With his third photograph Pieter comes to this conclusion: "My goal is to develop more self-confidence and demask the plan of the secret government or to realize that this is part of my disease and that there is no secret government". In Pieter's story façades play a transitory role. Initially his use of imagery from nature portrayed a polished story, lacking depth and with a make-believe quality to it. This façade protected him from premature self-disclosure. After reaching a turning point, in the second series of photo group sessions, Pieter came out from behind the shining imagery to tell of his delusions and raw suffering. He was able to find a way of dealing with this.

The function of the photo story: Pieter benefits from his participation in the photography group in two ways: he finds meaning in his life story and at the same time he learns from this exercise in openness and connecting with others. Overcoming his reticence, he found an inner locus of control over things: medication, becoming more self-confident and learning to master his fears. Visualising this in strong, emotionally “dense” photographs seemed to help Pieter to anchor this insight in his consciousness. Talking about it and sharing it with others made him feel less alone. The very image that eventually stood for newly won freedom, Pieter sitting on a fence, which in itself is a metaphor for façades, also served him, at an earlier stage, to present himself as someone who is “strong but alone.” The image reflects him as being inapproachable. Only through elaborating on his fears during the second series of the photo group sessions did this acquire emotional depth.

Afterword to Pieter’s story: After having participated in the photo group Pieter went through periods of psychotic decompensation during which he was re-admitted to the hospital. There were also periods of recovery. One year later he was interviewed again. He then reported that he could cope with his fears much better. He worked three days a week and was preparing himself to live in a sheltered group home, with some other clients and with nursing guidance, as needed.

Case 2: Judith photo story

Judith is a 40-year old woman sharing a house with others and supported by rehabilitation services to maintain her in an independent living situation. At times she suffers from psychoses. She is harassed by feelings of uncertainty and fear that hinder her in her functioning.

Semiotic analysis: In the first series of photo group sessions, Judith made photographs that illustrated that she functioned reasonably well and that she had reached a certain psychosocial stability. In the second series of sessions, she shifts her focus to her uncertainty about how to go on from here and get better/recover: “How can I find the old Judith, I once was, before I fell ill?”. One of Judith’s pictures shows her with arms raised in despair. Judith made pictures of body language to portray herself in poses that expresses uncertainty and her wish to become more assertive.

INSERT FIGURE 4

When Judith had herself photographed in these various postures, she exposed herself to the critical gaze of spectators. This is a paradoxical unity: daring to reveal her vulnerable self and, at the same time, concealing herself behind her overt anxiety. The contrast of connecting and withdrawal was also recognized during sessions of the photo group. She often was fearful of failing in the eyes of herself and others.

Hermeneutic analysis: The second round of the photo group sessions concentrated on what one hoped to realize in the near future. In her photo story Judith focused on her being able to drive again and be independent from public transportation. This was brought on by an unfortunate real life driving incident, in which Judith was arrested and had her driver’s license revoked. Driving down the wrong lane is somewhat ‘funny’, which seems to almost parallel the self parody in her photographs. Despite the theme of hope, Judith continued the role of helpless victim in her story, with lots of irony. There was no turning point in her script.

The function of the photo story: Judith confronts her anxiety by working it out in what seems a parody of helplessness, which is slightly different from the façade of being a victim. Her demonstration of helplessness may function as a protective mechanism, a strategy that aims at avoiding being held responsible for everything that might go wrong. Another possibility is that her performance evokes compassion. Helplessness does that sometimes. Perhaps this theatrical staging of her anxiety served to ease her feelings of being thwarted.

Afterword to Judith’s story: Six months later she and her mentor nurse were interviewed. Judith had made some progress. She had become more stable, although she still was troubled by panicky behavior at times. She had also taken up driving again. Contact with the nurses in the sheltered home had become more structured and that

helped her through the day. She had not adopted a new perspective on her life. She still longed to be the old Judith again.

Case 3: Tanja's photo story

Tanja is a 41-year old woman and has been a resident of a mental hospital for quite some time. The aim of her resocialization is that she resumes an independent living in her own home again. While still participating in the photo group she was dehospitalized but was soon readmitted again after accidentally using too much insulin that made her fall into a coma.

INSERT FIGURE 5

Semiotic analysis: Tanja took photographs of a tree felled by a storm, split in two over its full length. Her narrative about these photographs, with such enormous, dramatic and expressive power, was simply to say that making photographs of nature is what she loves to do as a hobby: "Making photographs of natural scenery gives me peace and relaxes me". In her photo essay she focused on a future in which she would make fine pictures with a semi-professional camera which she hoped to own. At that time, Tanja was due to be discharged from the hospital in the near future and live on her own again after a long hospitalization. On the one hand, this was what she eagerly wanted. On the other hand, she dreaded the idea that she had to be responsible for herself. She was torn between these two feelings and yet she could not show this in her photographs, because that would bring it out in the open. The storm felled tree begged for a more symbolic significance and might have been an opening to acknowledge the tensions Tanja felt. Tanja cherished being a photographer because it connected her with a past in which her grandfather had won prizes as an amateur photographer and a present in which photographs play an important role in keeping alive the memories of holidays spent with family in South-Africa. After a troubled period of hospitalization she now imagines living her life at home, in harmony with herself, and making fine pictures of nature.

Hermeneutic analysis: Tanja's story reads like a comedy, a type of story with a happy ending after earlier setbacks and suffering but with no great control over events on the part of the

protagonist (Wiklund et al, 2002; 2006). Based on contextual knowledge, we may doubt whether the image of stability in Tanja's story is realistic. Tanja became an out-patient during the last sessions of the second round of the photography group, but was soon re-hospitalized again after an insulin related coma at home. Tanja's story is a façade, her façade. It focuses on a carefree hobby, a family tradition. Troublesome circumstances that complicated her life were only shared "off the record". There was no integration of those into her photo narrative; it reads like a "they lived happily ever after"-story. Tanja is ignoring her suffering. The façade is one in which the protagonist makes her suffering invisible. *Tanja* seems to have withdrawn from her suffering to find a temporary respite. This is in itself an aspect of tragedy (Wiklund et al, 2002; 2006).

The function of the photo story: Tanja preferred to focus on the photograph of a semi-professional camera versus the split tree. This picture symbolized something important to her, a purpose in life to strive for. If her story focuses on goals that are not feasible right now, they may still function as a beacon in future toward which all her efforts can be directed. Almost more important than how things work out or how realistic her plans are is that her story serves to validate the image she clings to as a representation of her 'real' self and in this way helps her to "woodshed" her integrity (Strauss, 1989).

Clearly there are various ways façades can help people overcome suffering and vulnerability. In Pieter's case a turning point dissolved the façade. As Tanja's case showed us, the façade can be ambiguous, repressing the suffering, but can remain intact and act as a beacon for the future. Ultimately the image of being a photographer may increase her awareness of her own strength, which, in turn, may enable her to face her vulnerability.

Afterword to Tanja's story: Tanja did not recover fully from the neurological damage caused by the coma. She will probably never be able to live on her own again. Yet, true to her wish to make fine photographs she eventually bought the camera that she had mentioned in the photo group sessions.

Integration

There are stages of suffering in which persons move to and fro between suffering and desire and between hope and hopelessness. Transformation or *becoming* in suffering (Erikson, 2006) is achieved through confronting suffering and engaging in struggle. This, our study indicates, is often too intense and high-pitched for clients who suffer or have suffered from severe, long-term mental illness. With the exception of Pieter's, the cases we studied show that there are other forms of meaning making that do not entail a direct confrontation, but deal with suffering, nonetheless, albeit in a more roundabout way. In the case of Pieter there was a direct reflection on the sources of his suffering and a struggle to overcome his suffering. The façade of being strong and successful was dissolved, Pieter faced his vulnerability. He can be seen as "becoming in suffering".

In Judith's story her life and story seem to coincide. She seems to lament her situation and expresses this more with how she performs her story than with the words she uses. Just as Tanja, she tackles her suffering, but in an indirect manner, circling around suffering, avoiding a direct head-on confrontation with it. Yet, the irony of her comments on her situation opens perspectives for developing a relationship *with* her suffering.

The case of Tanja is more problematic. One might say that she is not *in* her suffering, but can stand besides it; she is *with* her suffering. She makes her suffering invisible through a façade; she disregards the gloomy prospects for the future, and cherishes the image of becoming an artist. She prefers her photograph of a camera, embodying her created self-image, instead of the split tree. She did not opt for confronting reality, by using the possible metaphoric meaning of the split tree, and tell us about her dilemma of choosing for a life outside the hospital with full responsibility or continuing in the safe institutional environment..

The visual narratives of Judith and Tanja indicate that instead of assimilating one's suffering one can step out of it and create a distance between oneself and one's suffering. In the face of suffering one can cling to a sheltered and cocooned perception of one's self and life story or find refuge in living in the present (Charmaz, 1991). One may argue that these responses are forms of façades, and that these façades can be highly functional. Living in the here-and-now

and just taking life's troubles and joys bit for bit, moment for moment, may be a survival strategy to help someone to cope. Another route that one can take is the flight forward into the future, staking everything on the hope that one day life will turn out fine and one can live fully and happily as is longed for and wished for deep inside. Is this not what Tanja's story is about? Clinging to images of "valued" life, may be more useful to restore or maintain dignity than a direct confrontation with the sources of suffering. Making suffering invisible through a façade, as Tanja did, can be interpreted as a positive effort to circumvent and go around her suffering and to connect again with a life still worth living. This may be a better strategy for clients who are already immersed in a severe, chronic mental illness.

Fredriksson & Eriksson (2001) view the distance that suffering creates between the person and his life, as a gap that must be closed in order to achieve a new wholeness. The cases we studied demonstrate that for some severe psychiatrically disabled people the opposite may be true. The distance that they placed between themselves and their suffering is a space that facilitated a feeling of control. This feeling of control may have been less effectively obtained with assimilation and integration of suffering. The distancing from suffering can also be considered a form of transcendence of illness and suffering, because it accepts them as facts of life that can't be changed. Confronting illness, in this sense, would be perhaps 'more expensive' in terms of spending time and energy on this, considering possible relapses and the occurrence of "bad days"(Charmaz, 1991).

DISCUSSION

Suffering and identity

Much of the literature on suffering departs from the assumption that only a direct confrontation with and assimilation of the sources of suffering can help people to overcome or transcend their suffering. Our study found that persons suffering from severe mental illness can

circumvent their suffering in representations of themselves that do not fit a linear development to more acceptance or assimilation of (suffering from) mental illness.

This seems to confirm what Veer van 't, Kraan, Drossaert, and Modde (2006) (2006) found when he investigated stigmatization processes of the mentally ill in the Netherlands: there is an important difference between an *established* identity and an *accepted* identity as a 'mental patient'. In his study most people had established identities as a patient, but only a small percentage had also accepted it in terms of attributing stigma internally. The three cases we analysed show that all three clients were fully aware of their being a mental patient, but also that their stories reflected this in diverse ways. Pieter attributed his impaired cognitive and social functioning to his schizophrenia, but did not accept it. Judith knew she was not like the old Judith, and lamented it. Tanja chose to 'forego' her being a mental patient: her representation was her identity 'beyond' being a patient. She seemed to be indifferent to the implications of her being a mental patient.

Resilience and strength

What we observe here is not the loss of identity that was found in a recent study by John Fleming et al. (2009) in which mental illness experiences expressed in a photovoice project were examined. Neither can we speak of a focus, as Fleming found, on the negative aspects of the mental illness experience, although Judith's story comes close to it. Overall, 30 out of 42 photo stories from our research had a positive orientation and bear witness to resilience and strength, rather than to despair and strong externally navigated experiences of stigma. We think that this discrepancy with Fleming's findings can be explained by the fact that clients in our study were asked what they valued in life rather than what mental illness meant to them. In addition, they went through a process of refining /repeating their narratives, which is distinctly different from a one-time rendering of their story. The process of showing photographs and telling one's story in the context of group sessions with fellow clients does develop the narratives and contributes to more insights into their feelings beyond a more typical account of the condition of suffering

from a mental disorder. This would confirm the transformative power that is realized through narratives (Frank, 1995; Hagedorn, 1996; Plummer, 2001; Lieblich et al, 2004).

Implications for research

The investigated cases show that categorizations in terms of façades are inadequate to encompass the richness and density with which a story reflects a person's life and the difficult circumstances that shape it. Much more research into personal narratives is required to enrich our understanding of personal representations of people suffering from mental illness. The role that internal and external attribution plays in these narratives deserves special attention, but is too narrow to realize a broader understanding of the potential of these stories to reassert meaning to a disrupted life. Stigma and stigmatization pose another research agenda that can build on insights from such research as outlined above.

Implications for practice

We have shown how visual narratives can help to gain a deeper understanding of suffering as experienced by psychiatric clients. Photographs and the significance endowed to the pictures by the makers, reveal meanings, including emotions and feelings, which are generally not tapped in an interview situation. Psychiatric clients are often very cryptic in interview settings. Question-and-answer interviews are often experienced as examinations and do not always produce meaningful data (Abma, 1998). It is, therefore, that Mertens (2002) pleads for more flexible and creative methods to be able to reach and include marginalized groups. Giving people a camera and inviting them to comment on pictures is less objectifying. Photography, as a medium, is attractive, because much can be said non-verbally; what can't be expressed in language, can be expressed visually. Imagery, like poetry, creates more room for the inexpressible and unspeakable experiences. Where these experiences find expression in façades it can be relevant for caregivers to discern the various forms that façades can take and what function they serve in protecting clients from a loss of identity. At the same time it is important for caregivers to be aware that the use of façades does not necessarily preclude a transformation

of someone's narrative and may even be one of its stages. This insight helps them to avoid the pitfall of static thinking that always threatens professionals who are used to working with diagnostic labels. It may sensitize caregivers to a more dynamic and diachronic perspective on traumatic experiences of mental illness and, in this way, contribute to less unilinear and more narrative models of nursing (Brockmeier, 2000; author, 2009). This means that instead of stimulating someone to confront his suffering, it may be better to be truly present, carefully listen and 'receive' a story. In this way caregivers can facilitate the process of meaning-giving by inviting the client to reflect on past experiences based on current needs, yet also look forward to the promise of the future.

CONCLUSIONS

Many photo stories in our study reflect the strength of clients, but this doesn't necessarily mean they seek a confrontation with sources of suffering. Façades can fulfil useful, sometimes transitory, roles. They protect the storyteller from too direct a confrontation with their suffering. Façades are sometimes an intermediary step in a development in which one learns to face suffering more directly, but they can also offer an alternative to confrontation. While Pieter is able to give his pain and suffering a place and gives up his façade, Judith and Tanja actually use façades to cope with their suffering, creating a distance through irony or a flight into the future. Cases like those of Tanja and Judith show that façades can contain indirect ways of tackling suffering that need not be based on rationalized verbal responses. Their rich accounts cast doubt on the received theory and throw light on future directions for theoretical research on suffering and the role of façades. Of course, rejection of a theory on the basis of two stories is extreme, yet it may lead to a revision of the theory or return to larger samples. Visual narratives compared with the real life context can reveal the hidden experiences of suffering, and help to understand the pragmatic role of façades in the lives of the severe mentally ill. As part of a

mixed methods model of inquiry, they offer a fruitful and appropriate approach for the understanding of psychiatric clients. Moreover the opportunity to tell their story offers clients a creative format and process to take on new roles and come to grips with their lives and suffering.

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Figure 1 : Pieter comparing his schizophrenia with a mouldered elm

Figure 2: Pieter sitting on a fench.

Figure 3: Pieter's caregivers and his doctor.

Figure 4: Judith desperately raising her arms.

Figure 5: Tanja's tree split by lightning.

Chapter 4: Moral learning in psychiatric rehabilitation

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The purpose of this article is to illustrate moral learning in persons with a psychiatric disability who participated in a nursing intervention, called the photo-instrument. This intervention is a form of hermeneutic photography. The findings are based on a multiple case study of forty-two patients and additional interviews with eight of them. Photo groups were organized within three settings of psychiatric services: ambulatory as well as clinical, all situated in the Netherlands. Data were analysed according to hermeneutic and semiotic principles. Two cases are presented. Findings show that voice and face are concepts that help to identify elements of moral learning in the rehabilitation process of persons with a psychiatric disability. During the process patients become more aware of their responsibilities towards themselves and others.

Key words: empowerment, moral learning, psychiatric nursing, rehabilitation, responsibilities

Introduction

Psychiatric nursing increasingly focuses on the rehabilitation of chronic patients. Since the 1980s there has been an increase in literature on rehabilitation of long term psychiatric patients.¹ Rehabilitation departs from the question how persons with a

psychiatric disability can lead a satisfactory life, even if there remain functional limitations in someone's psychosocial functioning. Often there is an emphasis on improving the skills and on adapting deficits in personal skills by 'making best use of residual abilities in order to function in as normal environment as possible (pp.3).'² More recently 'recovery' came up as a new concept that focuses attention not on limitations and making the best of one's losses, but on optimizing and utilizing possibilities, talents and other sources of strength.³⁻⁴ From severe mental illness and the handicaps it brings it is difficult to recover (but not impossible), but very often persons with severe mental illness do re-find the purpose of living a dignified life and thus recover from the role and identity of being a psychiatric patient who is thought to be pitied. We developed a nursing intervention on the basis of hermeneutic photography, which places emphasis on meaning making and construction of one's identity and future, rather than on the development of practical skills. Thus we contributed to a more recovery-oriented rehabilitation that focuses on strengths, hope and the furthering of making own choices. The development of this intervention preceded this study.

In hermeneutic photography people are asked to take photographs that tell something about themselves and their life world. The pictures allow them to 'capture meaning and symbolic life moments or events that can later be reflected upon, interpreted, and understood in new ways (pp. 26).'⁵ This is not just an aesthetic exercise. The photographs present what participants see as important; they illuminate personal values and desires.

As a nursing intervention the photo-instrument provides a means to nurses to structure and dose all the steps that patients make in their rehabilitation process. In this way

photography is a way to orient and direct care and support more to patients' demands and their lifeworld. The photo-instrument responds to the call for more ethics in care, because it puts *meaning* in the centre and stresses the importance of the physical and mental and social context of the patient.⁶⁻⁹ Renowned nurses and nursing scientists stress the importance of the patient narrative and the significance of the lifeworld paradigm.¹⁰⁻

¹¹ Not only within nursing but also in broader contexts there has been given much attention to the difference between illness narratives and disease narratives, the former encompassing the experience of living through the disease whereas the latter refers to the medical talk that objectifies the state of the body and the mind as cases of breaking down or disfunctioning that can be measured and diagnosed.¹²⁻¹³ Against the 'thin' medicalised narrative, Epston and White¹⁴, founding fathers of narrative therapy, suggest the need for 'thick' or rich narratives by which someone can reclaim his life from his problems. Arthur Frank, a sociologist who described his illness experiences at first hand, expressed it succinctly as follows: "If disease talk measures the body, illness talks [author: being the richer 'thick' narrative] tell of the fear and frustration of being inside a body that is breaking down."¹² (pp.13) Illness narratives can give voice to resilience and finding a new balance in one's life. In psychotherapy and other disciplines, narrative therapies have been developed that utilize the strength of narrativization to (re-)interpret one's life and further more authentic and adequate coping (e.g. White & Epston¹⁴; Gergen¹⁵; Anderson¹⁶). Within narrative therapy examples from literature and other arts are used while some of the concepts of narrative therapy influenced the development of therapeutic applications of the arts, as for instance in phototherapy.¹⁷

The photo-instrument we applied resembles the photovoice projects that have been adopted by the Centre for Psychiatric Rehabilitation at the Boston University as a participatory research tool to combat stigma in the lives of persons with a psychiatric disability.¹⁸ Our instrument differs, however, from photovoice in its focus on the individual process of meaning making as compared to its use for research, education, social change and public health.¹⁹ On the basis of the photo-instrument we organized photography groups for persons with a psychiatric disability in various contexts: long stay wards, day treatment centres and sheltered homes. The aim of this article is to illustrate how hermeneutic photography for people with a psychiatric disability can stimulate giving face and voice, and foster a moral learning process.

Theoretical framework

Psychiatric nursing and rehabilitation aim at empowering people with severe mental illness.

Empowerment as a dialogical process departs from a recognition that vulnerability, being dependent on each other and connectedness with others are inherent to human life.²⁰ We are dependent on others to gratify our needs and realize our values. We care for and about other people, nature and environment, because we are connected to them and dependent upon them, and may become vulnerable ourselves.²¹ From a care ethical perspective, autonomy is not related to one moment in time in which isolated individuals make conscious independent and rational choices, but perceived as an ongoing process of interdependent individuals within a communicative setting.²² This is captured in the notion of relational autonomy.²³ Nurses, for instance, can play a role in helping persons with a psychiatric disability to define themselves on the basis of authentic choices, their

historical identities and own perspectives, or, in other words enable them to become empowered.

Finding new goals in life is part of this rehabilitation process. For people with a psychiatric disability who have difficulties in verbalizing sometimes diffuse or emotional laden experiences and feelings, discursive rational methods of reflection and argumentation can be complemented with other communicative means to stimulate the process of goal setting.

In the context of this article we will focus on one particular approach, namely the photo-instrument. It may be a method complementary to the traditional verbal exchange in goal setting talks of practitioners of psychiatric rehabilitation with their clients. .

The photo-instrument resonates with narrative approaches to nursing ethics which emphasize the reconstruction of meaning through storytelling. Narratives are not neutral, but always reflect a personal standpoint and value commitment. Feelings and emotions are part of stories and can be understood as embodiments of what people value in life, what is important for them.²⁴ Nussbaum²⁵ argues that ethics starts in the context of everyday deliberations. In these concrete, practical situations it is not always easy to know what is right, because people are confronted with conflicting duties.²⁶⁻²⁸ Stories about illness, crisis and traumas not only *represent* the reality of the patient, but storytelling is a *vehicle* to give meaning to a dramatic episode in one's life.¹³ Illness narratives have ethical dimensions, because they reflect notions about the good life.²⁹ Co-creating and deliberating on (photo-)stories can foster a moral learning process. Participants engage in a relationship and dialogue, and this engagement may yield a relational narrative that helps a patient and his or her relatives to view an illness as a

catalyst for learning and growth, to assign an empowering meaning to an otherwise intolerably vulnerable situation.^{30,31}

Redefining one's existence in this way, a new perspective of the good life can be constructed. From *being* a psychiatric patient one may become a person *with* a mental illness: someone who has goals, strivings and ambitions that cannot be reduced to the status of being a patient. To say 'I am' is to say 'I want, I move, I do' (Ricoeur³², pp. 321). The notion of existence is associated with the notion of action. Suffering occurs where the power of acting decreases and someone becomes the *patient* of actions by others (versus being an *agent* of one's actions), as often is the case in mental illness when one becomes the object of treatment. Being an agent of one's actions, includes being subject to morality as the articulation of ethical aims in norms that help someone to characterize his action as good, just and wise.³² The process of formulating and recounting of actions that match with someone's concept of the good life can be characterized as moral learning.

Psychiatric patients often have to deal with stories that do not reflect who they are and undermine their sense of identity, integrity and dignity. Professional narratives tend to be plotted around setting a diagnosis and therapeutic actions that need to be taken to restore the patient's health. The patient's narrative is then reduced to a therapeutic narrative, which often leads to the feeling of not being heard and recognized. The concept of face reflects the idea that people want to be acknowledged as a certain kind of person.³³ Especially in informal talk people will share personal experiences in order to maintain respect and to prevent a loss of face that would incur feelings of shame. As this is an interactive process of construction one might speak of enacted identity narrative.³⁴ Narratives may represent a polyphony of narrative voices that make up our identity.³⁵ Their function may be twofold: a transformation of the self or a replay and an

upkeeping of *face*. We'll use the concepts of face and voice as operationalisation of the relational and ethical context of (photo-)storytelling.

Methods

We have explicated the methodological aspects of the intervention elsewhere³⁸. The implementation of the intervention preceded this study that focuses on one aspect: the role of the intervention in facilitating moral learning.

Design and setting

The design of the study was a multiple case study. It concerns the study of several demarcated units; each trajectory of a participant is considered to be a case. The photostories, that formed the core material of case trajectories were constructed on the basis of data gathered in nine photogroups (in total forty-seven participants: service users). These photogroups were organized by the first author in the years 2005-2008 within three settings of psychiatric services: ambulatory as well as clinical, all situated in the eastern provinces of the Netherlands. The photogroups were organized in several areas, varying from elderly care to adolescents who had gone through a psychosis. The main entry criterion was that participant should not be severely limited in cognitive and communicative functioning by psychiatric symptoms. Participants reflected an average sample of patient population when considering age, residence status (inpatients-outpatients) and diagnosis cluster. In most cases the photogroup was conducted by two staff members: two nurses or one nurse and an occupational therapist.

Intervention

The photo-instrument consisted of 2 sets of 8 sessions (group meetings) each. At the start the participants got a disposable camera and an assignment what to photograph. The first round focused on what participants see as important (or dear to them) in their lives (people, places, hobbies, etc.) and was completed with an exhibition of selected photographs. The second round focused on participants' wishes and their realization in the near future. In the first round attention was paid to what one values in life and what one has lost because of mental health problems. The main focus was however, more positively, on what one values in life.

Data collection and analysis

Out of the forty-seven cases forty-two were analysed; the other five withdrew from the study prior to completion. A composite research text was constructed for every case. The composite text combined the analysis of the stories that participants told with and about their photographs with the analysis of the observational data from the photoworkshops. In a number of cases these composite research texts were further enriched by individual interviews. Data from these interviews were also used for triangulation. Participants were selected with whom in-depth interviews were conducted till we reached saturation (n=8). The selection was based on the principle of variety; we wanted to gain a broad array of experiences. Parallel semi-structured interviews were organized with nurses conducting the photogroup and with personal mentor nurses of the interviewed participants (n=8). The interviews were audio-taped, transcribed verbatim and analyzed following a holistic content analysis.³⁶

Based on semiotics we considered the photostories as coded messages aimed at a concrete public that needed to decode the message again. Each message is multilayered. So, the photos themselves were also considered to be 'text' containing a message that was further explicated by tags that the photographers gave to them. We analysed the photostories on three levels: 1) as contents with certain recurring themes; 2) as mimetic constructions with references to the cultural storehouse of metaphors and collectively shared meanings and wisdoms; and 3) as social performance within the specific context of the photogroup in a mental health care institute. In the developing stories of these cases we found recurring patterns or aspects that made more sense when we interpreted them with the notions of relational empowerment. These patterns were confirmed by reading and rereading the composite research texts. The individual case reports were subjected to a member check with respondents to validate our analysis.³⁷ The combination of semiotic and hermeneutic methods and sources were used to triangulate the findings.³⁷

In this article we address two of the cases as an example of how the photo-instrument could be understood. Unravelling the two cases enabled us to explore the role of hermeneutic photography in moral learning.

Ethical considerations

The study was executed in accordance with the norms and regulations under Dutch legislation on medical research (the WMO-Law) and was approved by the appropriate Medical-Ethical Board. A proper informed-consent procedure was part of the research protocol. Confidentiality was assured by using pseudonyms and leaving out details that

would make identification easy. We obtained explicit written permission from the two persons whose photostories we used in this article for publishing the results, including their photographs.

Findings

The photostories of William and Benny

In this section we present the stories of two persons with a psychiatric disability joining the photogroups.. We opted for cases that showed various relations of face and voice. In our study (N=42) we found that in making their photo-stories about half of the participants explored in depth emotions and meanings and tended to evaluate their lives as told in their stories. The first case (William) we selected is representative of this group, whereas the second case (Benny) represents the other half of all participants that at first sight did not explore emotions and meanings in depth and was less explicitly in terms of evaluating one's life. In both cases the photo stories were supplemented with interviews.

William

William was one of the participants of a photogroup in a sheltered home where he lived for many years. He had been diagnosed with bipolar disorder and had been drinking excessively until very recently. In the first round he made photographs of his son, his deceased parents and fellow residents of the sheltered home; in the second round he concentrated on an issue that had been on his mind all the time, namely his alcohol addiction. He made photographs of settings where his drinking habits had been

triggered: the canteen of the sports club where he had been a pupil mentor. He also photographed a beer can, symbolizing his addiction. When asked to explicate his photograph, he said: ‘With the aid of Iris [agency for addiction care] I want to abstain from alcohol’.

INSERT FIGURE 1

Talking about the meaning of the photographs he admitted his addiction in front of the other participants in a way that resembled an emotional coming out of novices in an AA-meeting. ‘It is difficult for me to persist. When I am confronted with setbacks, then I don’t know how to cope. Setbacks discourage me . . . I need to develop more perseverance.’ His fellow participants witnessed his wrestling with his coming-out and William tested how far he could go by openly referring to his alcohol addiction. When he noticed that he was not denounced for it, he expressed himself more explicitly on the issue. He regretted that he had been unable to deliver a speech on the occasion of the opening night of the earlier photo exhibition (as he promised to do), because he had been drunk. He was ashamed of his ‘misconduct’ and made a vow that this would not happen again. He felt that he had betrayed his son, but stated that he would not do that again. He wanted him to be proud of his father and succeeded in remaining sober. On the opening night of the second exhibition he did deliver his speech. One year after this event he still was sober. His mentor in the sheltered home reported that every now and then William brought into memory his photographs and the vow he had made during the photoworkshop.

His failing performance at the opening night where his son was present had a strong symbolic meaning: again he had not lived up to expectations. One might say that the internal voice of the father was dominated by the voice of the alcoholic. However, the

photo-instrument called upon him to give a more complete and authentic representation of himself. The social context of the group also led to a moral call upon him that eventually triggered his rehabilitation. Since William had promised to give a speech, others expected him to do so. He did, however, not take on this responsibility, and felt ashamed to have failed in front of the orchestrated public. This loss of *face* triggered a determination to break away from his addiction. He then succeeded in giving *voice* to his responsibility as a father: 'I'm motivated not to touch alcohol again. My son means everything to me. I want to be a good father for him without alcohol.'

William went through a process of meaning-making in which he connected an image of who he was (a father) with a moral conception of the good life (fathers should take care of their children; one should keep a promise). The loss of *face* he had endured in his own eyes was transformed into his facing up the fact that he had an alcohol problem and presenting a new, responsible face to his fellow photographers in the group. The relational context of the group was then used by William as a safe place to *voice* his new (or rather his historical and more authentic) identity as a responsible father and show this image of himself, this *face* to others without shame.

The context of the group enabled William to hear other stories, helped him to open up to a less monolithic framing of his own story and find alternative perspectives.

Visualizing his addiction problem, for instance with his photograph of a beer can, reduced his shame. Speaking about his vulnerability made him realize what his danger zone was: 'It is because of family problems that I neglect my personal care and then I start drinking again.'

Benny

The second story is that of Benny, a young man diagnosed with schizophrenia and institutionalized after criminal offences. Benny participated in a photogroup with other people with a psychiatric disability in a long stay ward. The photographs he made, showed his wish for a life outside psychiatry. He made pictures of a detached bungalow with a lane leading up to a garage where he imagined his Ferrari to be.

INSERT FIGURE 2

INSERT FIGURE 3

He went to a Ferrari dealer and made pictures of his favourite model. Together with the photograph of the bungalow they formed the backdrop for a photostory about his wish to have a wife, share a family and have a life with material success. ‘Living together with a woman in a luxurious detached bungalow and have a Laborgini, Ferrar-Aston Martin “Vantage” parked on the lane!’ At the same time he made pictures in the hospital that portrayed him in a completely other light. There was a series of four or five photos of a long hospital corridor, each photograph taken at closer distance from the exit door.

Benny disqualified the photographs from a technical point of view. In the interview he explained the associations he had with these intriguing pictures. They stood for the time he had spent in psychiatry and the steps in his treatment to more autonomy and independence. ‘I wanted to show what schizophrenia means to me. . . [pointing to the door at the end of the corridor] There you turn around the corner and go outside.’

INSERT FIGURE 4

He hoped to go and live in a setting with more freedom in the near future. At the same time he was afraid of being stuck in psychiatry and, as in a nightmare, never to get to the end of the long corridor where the exit was.

Benny photographed an illusionary fantasy world in which he would have made it in life. The material successes -a Ferrari and a detached bungalow- he portrayed seem to have little to do with his actual situation: being hospitalized without sources of income. In terms of Goffman's³³ notion of impression management, Benny did not persuasively succeed in constructing a credible face. The face he presented seems foreign to his own history. Benny clearly didn't acknowledge his limitations. At first sight Benny's photo essay was not even a mere representation of the self, let alone a transformation in a process of personal rehabilitation and empowerment. So it seems. But then there were other photographs, which, although disqualified by him, related to the reality of the hospital and his life as an inpatient. These were the photographs of the hospital corridor. When the nurse probed him for the feasibility of his grandiose future plans, he was able to outline that he had to make an income of his own and that the first step towards his luxurious place to live was a room outside the hospital in a sheltered home. This entailed the moral intuition that success in life means taking first steps, developing oneself and being responsible for that: 'My challenge is to resume my life, return into society and function on my own again.'

When asked how to realize his future wishes, he answered: 'My wish is to be happy with someone and have comfort. Whether this will be feasible, I hardly think so. I dream about a 'happy' future with a wife at my side.' What he made clear here is a longing for being connected with someone else, for love and happiness. This has a moral dimension (being happy with someone) besides a more hedonist consumerist connotation (have comfort). Although he didn't allow the more authentic voice to come into the foreground, there was some play with different voices or aspects of his identity and

history. In the meantime Benny still needed to bolster his unstable identity with a *face* attributed with conventional symbols of success. This façade probably protected him from a too painful awareness of his vulnerability. It gave him the experience of personal control instead of the dependence he felt as a patient.³¹

For Benny as well as William the social context of the photogroup acted as a motivator to discover and take on responsibilities, both for their own life and towards others. It provided a context for moral learning. William, for example, rediscovered that not keeping a promise is morally wrong. His feelings of shame are an embodiment of the value he endows to being a good father and being reliable as a person. Benny learned that what really matters in his life is not material success and blowing up one's image, but being truthful, beloved and giving love to others.

At the end of the group sessions, William experienced more control and autonomy, because he stopped drinking. Eventually Benny took up a job as shop assistant as a first step to earn his own living outside the hospital setting. Although these results may not seem impressive in terms of objective empowerment, they can be regarded as important developments in the lives of both men. These changes can be seen as moral learning, since they entail new visions of what counts in life. Reflecting on the aims of a good life helped William and Benny to restore their self-esteem. Their reflections were paralleled by actions and these actions followed moral norms deduced from their aims to realize a good life. This enabled them to regain self-respect and respect from others.

Discussion

We may question whether the developments in the men were more than just ‘impression management’, a term Goffman introduced to denote social behaviour aiming to reconstruct a certain identity. For example, Benny seemed to be preoccupied with keeping up face and impressing others with his playboyish obsession with Ferrari’s and luxury bungalows. However, in his story there were also shifting meanings. Underneath the symbols of material success he was led by ethical values of love, and connectedness with other people. These values gave rise to inner doubts and longings that he did share with others in the group, and which did play a role in his rehabilitation process, although he did not select them for public showing in the photographs. It seems here that Goffman’s³³ concept of impression management fails to convey a full understanding of the dynamics in rehabilitation. Goffman’s notion of impression management can be criticized from hermeneutic philosophy. Philosophers like Ricoeur³², Levinas³⁹ and MacIntyre³⁴ have reasserted the importance of ethics to sustain psychological continuity and experience moral identity in one’s life.

According to Levinas³⁹, face is also the expression of our vulnerable inner self. William, for instance, was known to have a drinking problem for a long time, a fact that was even reasserted at the opening night of the first exhibition. Later he showed this vulnerability openly, and this met respect within the group. He then promised not to drink anymore and not let his son down in the trust he put in his father. In a face-to-face contact face can invoke an involvement that has an ethical dimension and surpasses the civic respect of face, as pointed out by Goffman.³³ We want someone’s face to appear as authentically representing someone’s selfhood, not per se meaning the same-ness that we recognize from what we know, but the person as he is ‘meant’ to be and that we expect to be present deep down.³² A face distorted by suffering presents a moral appeal.

In an ethical approach of care this will result in attention and respect for the concrete and unique person with his own perspective on the world, his own story in a certain context, on a certain moment and in a certain mood.

Voice stands for a more discursive aspect of identity. It refers to 'being heard' where face relates to 'being seen'. 'Being heard' supposes someone listening. Having someone who listens to you without him suggesting solutions, can have a deeply felt comforting and healing effect.⁴⁰ Just as face refers to the possibility that it represents authentically someone's selfhood or that this is masked, the concept of 'voice' reflects the idea that one can speak with different voices that stand for different orientations or perspectives, some of them being more authentic than others, meaning here: more fitting one life history, one's wishes and ambitions.⁴¹ It happens that persons with a psychiatric disability cannot voice these aspects of their selfhood. Suffering isolates people and tends to contain them in themselves. Feelings of shame and loss of face can impinge on someone's capacity and openness to give voice to other strands of identity than those that are usually expressed.

Suffering has a moral significance, relating to the life limitations the person is confronted with in terms of his values.⁴² Carnevale therefore proposed that 'empathic attunement' should be cultivated by health care professionals as an instrument of understanding the significance of the experience of suffering for a person. This empathic attunement requires a constant attentive engagement with the sufferer's phenomenal world in an attempt 'to sense the meanings he or she associates with a particular emotion, such as suffering' (pp. 181).⁴² The contribution of hermeneutic photography lies in the reiterative and persistent character of focusing on meaning making and giving sense, thereby making transparent that creating truth is a matter of constructing narratives. Beside the autonomous hermeneutic process of meaning

reconstruction through photographs, the interactional positioning that is accomplished by telling a story and discussing it with the nurse facilitator and the audience of fellow participants is responsible for more credible and more realistic stories, thus fighting a tendency for grandiosity. Truth ultimately transpires through changes in real life. In the case of William we see he gave up drinking alcohol. Benny eventually took up a job as shop assistant as a first step to earn his own living outside the hospital setting.

Implications for practice

By generating and acknowledging the photostories as personal stories nurses show that their narrators are worthy to be seen and heard, and that they needn't be ashamed and withdraw from contact. This is essential for rehabilitation, because it invites someone to come forward and resist the clinical gaze of professionals. Loss of face occurs when someone is only recognized as a patient. Loss of face causes feelings of shame and (self-)stigmatisation that bereave someone from the hope that his life can change. Restoring reciprocity in the contact between caregivers and people suffering from mental health problems is important to call forth a face that the person himself also recognizes as more authentic and of which he is not ashamed. When patients can connect again with more authentic identities and values this will rehabilitate them. Nurses can help patients in this process by creating a safe haven and communicative platform where patients experience a space for reflection on their life.

Photography, as a medium, is attractive, because what cannot be expressed in language, can be expressed visually. Imagery, like poetry, creates room for otherwise inexpressible and unspeakable experiences.

Summing up the concrete aspects of nursing that hermeneutic photography can make a contribution to, we distinguish:

1. an attitudinal aspect: a reciprocity of respect that is conditional for a therapeutic alliance, necessary for working together towards the promotion of better health and well-being
2. the creation of a space for reflection that helps patients to construct meaning
3. a method that supports patients with creative non-verbal means

Conclusion

In this article we have tried to show that rehabilitation is linked to moral considerations about one's moral identity and one's life. Crucial in this process is a reflection on the kind of person one wants to be, and how this relates to what one considers to be a valued life and whether this still can be realized. Whom do I care for, who do I want to be for others? Is there a meaningful role for me where I am acknowledged as a person? What is important for me in life? Can I realize that with my handicap? This moral thinking is part of an interaction with the social environment in which persons with a psychiatric disability wrestle to find new credible selves.

The photo-instrument can be a catalyst in the process of finding a more authentic and credible identity. Taking responsibility for one's life (the hallmark of rehabilitation and empowerment) and that of others will only happen if one is recognized as a unique person and a credible conversation partner. In the end moral learning is crucial to rehabilitation and psychiatric nursing.

Conflict of interest statement

The authors declare that there is no conflict of interest.

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Chapter 5: Living with severe mental illness: perception of sickness

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Abstract

Aim. This article is a report of a study on how participation in photo groups influenced the perception of the impact of sickness on daily life.

Background. Living with severe mental illness can have a strong impact on daily life and the experience of self. In combination with self-stigmatization, this can lead to a sense of being no more than a patient.

Method. A mixed-methods design was used to measure the perception of sickness impact. Consumers of psychiatric services participated in photography groups that aimed at integration of illness and developing new goals in life. These groups were conducted by nurses and data were collected between the years 2005 and 2009.

The Sickness Impact Profile (SIP) questionnaires were completed by the respondents before and after intervention. The SIP was used to differentiate between respondents who perceived less impact of illness on their daily lives after following a photogroup and those who did not perceive so or remained the same. A sample of these three groups was used to complement the quantitative findings with in-depth interviews with consumers and mentor nurses.

Results. Findings indicated absence of important changes in the sickness impact scores except in the domain of mobility. Consumers did, however, show signs of progress in terms of increasing openness, understanding of their feelings and situation and abilities to cope with them.

Conclusion. Participating in photo groups can help patients get along with their

life and make it more bearable. No signs of demoralization and self-stigmatization were found.

Keywords: impact of sickness, mental illness, mixed methods, photography, rehabilitation, stigmatization

Summary statement

What is already known about this topic

- There are only a few examples of the therapeutic use of photography in health care that are applied to (semi-)institutionalised patients suffering from severe mental illness.
- Although the influence of stigma on self-esteem and well-being is well-studied much is still unknown about how persons experience a life with mental illness.

What this paper adds

- The therapeutic use of photography has great potential for nurses to engage in a dialogue with consumers on their strength and how to live a ‘valued’ life.
- Long stay patients showed no evidence of self-stigmatization and demoralization when assisted with a creative, strength-based approach.

Implications for practice and/or policy

- Nurses should be better acquainted with and trained in the use of creative and non-verbal interventions
- The use of photography in nursing research is recommended.

INTRODUCTION

Mental disorders play an important role in the lives of people who suffer from them. Mental disorders effect how people perceive their self-image, which they often increasingly define in terms of a deficit functioning in daily life and their roles as patients (Adame & Hornstein, 2006). This may lead to withdrawal from social life in order to protect the self from further degradation (Fisher, 2008). Declining social activities, however, are likely to reaffirm to a person that he is a patient and not functioning well, thus contributing to a further lowering of self-esteem and a focusing on one's shortcomings, illness' symptoms and other weaknesses. However, there are many other aspects of the identity and personal history that are of importance. Where these are overshadowed by illness they deserve to be put into the picture again. To this end an approach making use of photography was devised and implemented in mental health care. We have called our approach the photo-instrument. The photo-instrument aims at facilitating a process of meaning giving that creates an awareness of a 'valued life', that is: there is more to life than being a patient with a mental illness.

Although there are more examples of the therapeutic use of photography in health care (Hagedorn, 1996; Radley & Taylor, 2003; Wang & Burris, 1997 ;Weiser, 1993) the photo-instrument is one of the very few that is applied to (semi-)institutionalised patients suffering from severe mental illness.

INSERT FIGURE 1

BACKGROUND

Conceptual framework

Living with chronic illness can have a strong impact on daily life and the experience of self (Charmaz, 1991; Riessman, 1990; Williams, 2001). With severe mental illness the impact is often huge (Hinshaw, 2007); the illness disrupts the life story, and necessitates an evaluation of one's identity. Suffering can result if one becomes aware of the losses. The effects related to the symptoms of mental conditions themselves may be augmented by the effects of stigmatization (Hinshaw, 2007; Corrigan & Watson, 2002). The negative conceptions and stereotypes of mental illness held by the general public, often lead to social rejection. Research into the effects of stigma on people with mental disorders has shown that stigma often contributes to lowered self-esteem and depressive feelings (Hinshaw, 2007), although other responses are possible too (for instance righteous anger that fuels becoming active in advocacy and empowerment efforts). Persons with mental disorder often have expectations of rejection and stigmatization (Wright, Gronfein & Owens, 2000). They sometimes hold the same views to mental disorders as the general public (internalized stigma). This compound of actual rejection and stigmatization, perceived stigma and internalized perceptions can lead to coping strategies of secrecy and social withdrawal (Hinshaw, 2007; Corrigan, 1998), decreasing the chances for adaptive responding of the person with mental illness (Link et al., 1989) while at the same time protecting them from further lowering of self-esteem. Corrigan and Watson (2002) described still another group that needs to be considered: those persons with mental illness who don't suffer from a hurt sense of the self and are not energized into righteous anger, but instead seem to show indifference to the impact of stigma altogether.

Much is still unknown about how persons experience a life with mental illness. We therefore stepped down from stigmatization to an underlying level, namely that of meaning giving and personal representations per se.

THE STUDY

Overall information

The present study is part of a larger research project that aimed at an understanding how the photo-instrument facilitates consumers to find and express meaning in their lives.

We organized photography groups in three psychiatric hospitals in the eastern provinces of the Netherlands during the years 2005-2009 (in total 16 groups;74 participants who also partook in the study).

Participants in the research were consumers of psychiatric services, suffering from severe mental illness but no longer troubled by acute symptoms.

The intervention

Consumers come together in a photography group with weekly sessions over a period of 8 weeks. Per group about 6 patients join in. The groups are moderated by a nurse. Every participant receives a disposable camera and an assignment to make photographs of what is important to him and also of aspirations he/she entertains (see example in figure 1). The participants are interviewed by the nurse about the meaning of their photographs. For a more detailed description of the intervention we refer to publications elsewhere (Sitvast et al., 2008, 2010).

Aim

The aim of the study was to assess how the photo-instrument effects participants' perception of the impact of sickness on their functioning in daily life now and in the future.

Design

In the present study we used a sequential exploratory design with mixed methods by first analysing quantitative data that rendered an insight in the range and frequencies of the phenomenon studied and then using this insight for a selection of data in a qualitative exploratory approach.

Methods

As a first step in our sequential approach quantitative data were collected and analysed. For the whole sample of participants in this study an analysis was made of the distribution of demographic variables, residence status and diagnoses. Then the analysis focused on the self image of patients across situations of functioning in daily life. We measured changes in the (self-)perception of the impact of illness on patient's daily functioning: the so-called sickness impact profile (SIP). A standard validated questionnaire (the SIP68) was used for this (Bergner et al., 1981; De Bruin et al., 1994; De Bruin, 1996; Nanda et al., 2003; Hacking et al., 2006). The SIP measures impact of sickness on daily activities (Nanda et al., 2003). It measures the respondent's perception of the impact of his/her sickness on six domains of daily functioning, ranging from

control over somatic and motor functions to psychological and behavioral functions, regulations of emotions and mobility.

The SIP68 was filled out before and after participation in a photo group, thus showing possible changes in self-perception during the course of a photo group. T1 was administered at the beginning of a photo group, T2 was administered at the time that participants finished the photo group and T3 was administered 6 months after having finished the photo group.

Sample

The primary sample was made up of all patients (N=74) who participated in photo groups that were organized by the first author in the years 2005-2009 and consented to participation in the study as well. Inclusion criterion was that patients were not in an acute crisis phase and were not troubled by acute symptoms. After computation of the SIP-scores we reduced data by ordering individual SIP-scores in two categories, namely high and low scores within the primary sample. This made it possible to compare scores at T3 with T1 and to differentiate patients who at T3 had changed perceptions from those who had not. We focused on the mobility range as this was one of the categories in which we found significant changes in perception of the impact of illness on daily life.

We distinguished:

1. patients who showed a reduction in perceived impact
2. patients who remained on the same level
3. patients who showed an increase in perceived impact

This division of the target population enabled us to find a good sample for the qualitative part of the study. If the statistical computation of SIP-data would have been

the basis for the further steps, the research results would have been far less useful/informative, given the small number of cases included. From all three groups together we selected 8 patients for further interviewing in order to explore in-depth differences and similarities in perception across the subgroups or strata. Purposive sampling was used because we intended to select specific cases that will provide the most information for the questions under study (Kemper, Stringfield & Teddlie, 2003). Our purpose was informed by theoretical considerations that made us focus on in-patients and especially long-stay patients. We assumed that the length of their stay in a hospital contributed to a greater susceptibility for self-stigmatization than would be the case for outpatients (Bradshaw, Armour & Roseborough, 2007; Hinshaw, 2007). This resulted in interviews with inpatients only. As we divided the research population in strata we can speak of a stratified purposive sampling (Kemper et al., 2003). For the sake of triangulation of interview data we also interviewed caretakers, mostly mentor nurses that were closely involved with the interviewed patients. We asked them how the patients they tutored were functioning and how they were doing in more general terms.

Data analysis

The quantitative data were analysed using SPSS version 17.0 (SPSS IBM Corporation, Somers, NY, USA) to compare averages in groups. Non-parametric techniques (Mann-Whitney) were chosen because of small numbers and skewed data.

The qualitative data were analyzed using thematic content analysis based on comparisons within and across cases.

In our analysis we operationalized our main research question 'how the photo-instrument effected participants' perception of the impact of sickness on their functioning in daily life now and in the future', as follows:

1. Would consumers' perception change with the formulation of photo-stories and the experience of participation in the photo group, that is: will there be a reduction of perceived impact of illness?

We postulated that consumers perceive their lives as having been hemmed in by illness experiences to a degree that reflects also a demoralization and (self-) stigmatization as a patient.

2. If we don't find a reduction of perceived impact of illness and may-be even find an increase, can we then attribute this to demoralization and self-stigmatization?
3. Has participation in the photo group generated other, may-be more positive ways of looking at one self and how to cope with illness even where the perceived impact of illness remains the same or has grown larger?

Ethical considerations

The study was executed in accordance with the norms and regulations under Dutch legislation on medical research (the WMO-Law) and was approved by the appropriate Medical-Ethical Board. A proper informed-consent procedure was part of the research protocol.

Validity and reliability

Following a hermeneutic perspective we used the notion of "credibility" (Lincoln & Guba, 1985) to ensure the validity of our study. Procedures to ensure credibility included a member checking of interview texts with the research subjects. In the interviews we discussed their outcomes of the SIP. Findings were then tested against

what mentor nurses reported in parallel interviews. Trustworthy interpretations were achieved through reflexivity in an re-iterant process of discussion between first, second and third author, peer review and theoretical sensitivity (see also Strauss & Corbin, 1998).

The SIP68 has been tested for validity and reliability in different diagnostic groups by De Bruin (1996). Their findings were satisfactory: the SIP68 appears to be a reliable instrument. Internal consistency was assessed by means of Cronbachs alpha: 0,92 (N=2371). Test-retest reliability was assessed by means of the intraclass correlation coefficient: 0,97 (N=51). Content validity: all aspects of the SIP136 are covered by the SIP68 and represent all three categories of health (physical, psychological and social) that are considered to be relevant in the WHO definition of health. Overall criterion validity as assessed by means of Pearson's r between T1 and T2 was 0,73 (De Bruin et al., 1996). These findings were by and large confirmed in more recent studies (Nanda et al., 2003; Hacking et al., 2006).

RESULTS

Changes in perception of the impact of illness

At T3 evidence could be found for (photo-) storytelling to contribute to a limited reduction of the perceived impact of psychiatric illness on the 'normal' functioning in daily life (table 1). We did a non-parametric test to compare scores of the SIP-

questionnaire at T3 (N=48) with T1 (N=74). Dropout from the study occurred mainly at T3 (six months after completion of the intervention) and did not reflect dropout from the intervention. Drop-out at that time (N=26) can be ascribed to reduced study adherence due to the lapse of time and loss of contact.

We found that a significant reduction occurred for the whole population in the domain of mobility despite the small number, thus signalling less impact of patients' illness on their daily functioning in this domain (mean T1= 1,43 mean T3=0,90 Diff. T1-T3 sig. Mw U= 1416; d.f.=47). This domain is concerned with the influence of health and sickness on daily tasks like shopping, house cleaning, taking care of personal business affairs and social calls on relatives and friends. There is no significant difference between pre and post-test situation in the other domains. We did the same test with subgroups, now distinguishing inpatients from outpatients and found a significant reduction, for social behaviour in the out-patient group (mean t1= 4,57 mean t3= 2,65 Diff. T1-T3 sig. Mw U= 365; d.f.=25). Because of small numbers residual gain could not be calculated.

INSERT TABLE 1

Differentiation into residence status was relevant because in the photo groups we included participants from very diverse backgrounds that ranged from elderly people that visited a day care centre after having been treated for a depression to adolescent youngsters who had a psychosis and attended day treatment programs to long stay patients who sometimes were hospitalised for years (table 2). They all had a severe mental illness in common, but their perspectives for the future differed enormously as also did their degree of recovery. Some of them lived in sheltered homes (long stay), others were temporarily hospitalized or lived at home and were outpatients. Patients'

levels of functioning and their perception of it therefore differed widely. This was reflected in the SIP-scores. It is relevant to note that the group of outpatients showed a statistical significant reduction in patients' perception of the influence of illness on social functioning in relation to other persons (spouse, children, "other people" in general). Sexual activity, visiting friends and activities in groups of people are items in this category, as well as doing chores in and around the house and recreational activities. For inpatients the focus on a domestic situation apparently didn't reflect their present situation of living in a hospital setting. Thus they may not have recognized themselves in the statements of the scoring items. The opportunity for entertaining hobbies and leisure activities for instance is often limited for inpatients who have little private space to call their own and little money to spend.

INSERT TABLE 2

Explaining the limited reduction of the impact of the illness

Can we attribute the absence of significant changes in most domains of the SIP score (except for mobility) also to demoralization and self-stigmatization? Ordering individual SIP-scores in two categories, namely high and low scores we were able to differentiate patients who at T3 had changed perceptions from those who had not (table 3).

INSERT TABLE 3

From this differentiated population we drew a sample of 8 patients with which we held interviews. Their mentor nurses were also interviewed. These patients were divided over the substrata as follows (table 4):

INSERT TABLE 4

We interviewed long stay patients and their mentor nurses only since there was no statistically significant reduction found in their SIP scores. These interviews offered us the opportunity to explore how a group of inpatients describe their social functioning and mobility.

In these interviews we were able to identify several aspects that recurred with all respondents. These are:

1. the importance of seemingly banal activities
2. the accuracy of how patients describe their limitations and restrictions
3. patients' striving for a higher level of functioning
4. patients' mentioning of other forms of coping

1. The importance of seemingly simple activities.

We asked our respondents how they went on in every day life to see whether the limited reduction of the impact of their illness on their lives was a matter of demoralization and self-stigmatization. All respondents answered with anecdotes and examples of simple, but important activities related to their wish to do the same ordinary things that other people, not troubled with psychiatric symptoms, would do. Judith, for instance wanted to go to a birthday party:

“My sister-in-law celebrated her birthday. I drove up to her house in a fit of giving it a try and see where we would end up.”

Linda, who lived in a sheltered home, answered to the question of the interviewer how she would notice it in her daily life if she were to perform better than she did until now:

“I’d live through the day better than I used to do...just doing the things that have to be done [...] looking after myself and also finding a pastime.”

We discovered that seemingly simple things in life like going on a birthday visit, running a household, doing errands and preparing one’s own meal for instance- related to patients’ hope for a return to a ‘normal’ life and that these tasks could be charged with emotion and tensions, because of experienced restrictions in psychological and social functioning.

“On some of these days I don’t feel well [...] I don’t know what happens to me then [...] even washing the dishes [can be difficult]. I have to press on[to get it done]” (Judith)

“I have these obsessions, for instance: I must keep my hands closed. I have a lot of trouble with reading, writing, making phone calls, etc. [...] There are many things I feel obstructed in, but which I would like to do.” (Rose)

2. The accuracy of how patients describe their limitations and restrictions.

Patients' reports on their functioning were in line with the way how they had scored the SIP-questionnaire and corresponded with their photo stories. Almost always patients gave an accurate estimation of the relationship between psychological and social restrictions and their capacity to perform every day activities.

"I'd like to live together with my girl-friend [...] Living together is difficult if you don't feel well. Spirits and voices cause me a lot of trouble". (Orlof)

Mentor nurses confirmed the correctness of estimations given by their patients, although they labelled these relationships in more professional terms. Orlof, for instance, knew very well how his voices (spirits) stood in the way of normal functioning. His mentor nurse, however, had a slightly different opinion about this relationship by emphasizing the social consequences:

"Finding a volunteer's job for Orlof we want him to mingle with other people instead of staying in his room and calling astrology telephone lines all the time. But as the situation is now, Orlof only agrees to working with other young people just to convince them that they should attune their thinking to another (esoteric) reality."

One aspect of how patients perceive their functioning is whether they recognize progress or deterioration over time. We noticed that patients often had an open eye for progress in some areas without disregarding still existing deficiencies in others. Linda, for instance reported:

“I have a lot of contact with other people in the shelter. I used to be in the communal livingroom day and night. Today I retire to my own room in the evening.” (earlier she found it hard to be alone)

At the same time Linda acknowledged: “Actually I’m not doing that much. I don’t have a regular program how to spend the day and household chores still remain unattended.”

So, despite the more realistic view of their disabilities the patients did not show signs of demoralization (they still saw progress) or self-stigmatization (they believed they were more than just a patient).

3. Patients’ striving for a higher level of functioning.

Almost all patients believed that they could attain a higher level of functioning and they all had goals that showed how they still strove for a more independent and ambitious life.

“I keep finding things difficult [...] concentration for instance: reading is very hard for me. It will be difficult to live on my own, that’s what my psychiatrist told me, but I want to fight for it to make it happen.” (Tanja).

“I’m working on it to go on a holiday with Radar (travelling agency for patients) to Greece or Spain this September or October.” (Benny)

Sometimes their mentor nurses indicated that they tried to help their patients to accept that a return to an independent life may be unrealistic. Not the patients’ estimation of

their present functioning was too optimistic in these cases, but expectations of the future, according to the nurses. This is for instance what the mentor nurse of Pieter said about him:

“Living alone in an apartment of his own is very tough for Pieter. It gradually dawns upon him that it may be not wise to do that.”

Patients may keep realistic images of their functioning in daily life and at the same time hold expectations about the future that are based on a more wished-for life that comes closer to their ideas of their values, as we also found in the photo stories themselves (Sitvast et al., 2010).

4. Other forms of coping

More openness and connection

Some of the patients we interviewed perceived the impact of their illness to be worse 6 months after participation in a photo group. Pieter, for instance, recorded that he didn't fare well at the moment of filling out his SIP scores, but then we must also take into account that he had gone through ups and downs and had been in and out of the hospital during the last months. And with him other patients in our study were. The direct impact of severe mental illness on their lives, as measured with the SIP, is not likely to dwindle in size very easily and maybe only do so in the long run. However, we can see other strides forward in the mean time. There is more openness to others and the idea that they, especially their mentor nurse, understand what they go through helps them to hold out. There has been a growth in contact that makes it easier for them to depend on others

when they need it. In William's case the mentor nurse shared an intimate event with him: his wrestling with his alcohol-addiction and finally his coming-out and telling it through a photo story (see Sitvast et al., 2010 for the more extensive case study). The openness and sharing his vow not to drink anymore sustained him through difficult moments ever since and kept him from feeling a good-for-nothing patient. With Judith the positive result lies with a more sensitized understanding of the nurse and less with Judith coping with her situation in a better way. However, indirectly this helped Judith to receive a treatment that matched better with her coping style.

Trust in one's future and determination

Talking about what one wishes and values doesn't seem to demoralize participants, but on the contrary helps some of them to regain trust in their future and determination.

With Tanja her being involved in photography helped her to remember the skills she still had even where she had lost many others. It gave her something to live for and lent her a determination to fight for an independent life. For her photography itself had a strong symbolical meaning.

Sorting out confused feelings

Linda, who was diagnosed as having a borderline disorder and who found it extremely difficult to disentangle her confused thoughts and feelings, reported:

"Because of the photo therapy things became clear for me as I wrote them down. I had this Aha-feeling of understanding them a little better. It is a pity that I lost the paper [with my texts]I because then I could have looked them up again and relive this Aha-feeling again."

This understanding didn't translate itself into a better way of handling her feelings, indicated her mentor nurse. Rose, who was diagnosed with autism, resembled Linda in her appreciation of how the photo group helped her to sort things out.

"I like it to mark time as it were and then see what you have. Taking time to see where you stand. It was nice to do that with photographs and the talking that goes with them. Afterwards you can read it and reread it and I liked it to have the things sorted out this way."

Rose valued this so much that she kept collecting images and photographs of activities she undertook, using them as prompts in discussing her ambitions and wishes with her psychologist until this initiative petered out again because of many changes in caregivers that treated her.

DISCUSSION

In the literature is reported that due to self-stigmatization some people with severe mental illness define their self-image increasingly in terms of a deficit functioning in daily life and their roles as patients. This can have the undesirable effect that people with a mental illness sometimes give up on being a person *with* an illness or handicap and become their illness or handicap (Gagne, 2004). This is not what we found. Our patients have a pretty realistic view on their limitations and how these affect their daily functioning. Yet, this does not lead to adjusting the self-image in a negative downward

spiral to a numb identity as chronic patient. Patients still long for a 'normal' life in which they can make independent choices, run their own household, have meaningful activities at their hands, see friends and family and maybe go on a holiday every now and then. In this respect patients fit the category that Corrigan and Watson (2002) had in mind when they distinguished a third group of patients that showed indifference to the impact of stigma.

A limitation of our study is that we interviewed only patients from the group that was hospitalized or lived in residential settings. However, it can be expected that this group of patients is likely to be subjected to processes of (self-)stigmatization more than the outpatient group. We therefore assume that, like inpatients, outpatients also have a realistic estimation of the impact of illness..

The SIP questionnaire records the perceived impact of illness and thus entails a direct confrontation with one's shortcomings. Besides the many somatic items that are hardly relevant for psychiatric patients there are many other items that may give an emotional arousal, because of the direct confrontation with malfunctioning. This is an example of a more general problem for health research, namely our dependence as researchers on the use of validated instruments that have a generic character and therefore can't be tuned to specific contexts and characteristics of interventions. This drawback can, however, be compensated by using mixed methods, as we did in our study. Findings from (qualitative) interviews can be used for triangulation, like the corroboration we found between the SIP scores and qualitative data. Yet, our study also showed that the sets of data have a value of their own and are additional to each other. Using interviews next to the survey-like SIP questionnaire we aimed at complementarity of data interpretation

and development (as described by Greene, 2008), meaning that evidence from one data set was not only corroborated from data in another dataset, but also enriched and supplemented with more detail and other information. Findings from the interviews complemented the SIP scores and vice versa. A cyclic way of working in which the outcomes of the SIP scores informed the design of the qualitative study helped to integrate the data sets. The result is a more comprehensive understanding of the subjective experiences of men and women suffering from severe mental illness. On the basis of our study we conclude that a complete sequential separation of the qualitative and quantitative components of research is not possible nor desirable. We noticed in our study, that the different components “tend to grow ‘tendrils’ backward and forward, integrating both qualitative and quantitative elements into all components of the research”(Maxwell & Loomis, 2003). We conclude that ‘resonance’ among the components of a mixed methods design has a value in itself.

CONCLUSION

Patients suffering from mental illness may develop a self-image in which deficits in functioning hold a central place. We expected that the photo-instrument would have a therapeutic effect on the perception of patients of the impact of their illness on their daily functioning. This effect was indeed partly found in the outcomes on the Sickness Impact Profile that were measured in a pre and post test situation. We found a statistically significant perceived reduction of sickness impact among outpatients in the domain of social activities. For all patients included in our study we found a statistically significant reduction within the mobility range that included daily tasks like shopping, house cleaning, taking care of personal business affairs and social calls on relatives and friends. We found no effect of the photo-instrument in other relevant SIP domains like

psychological autonomy and emotional stability. Complementary interviews with 8 selected patients and their mentor nurses indicated that patients do progress in terms of an increasing openness and understanding of their feelings and situation, and abilities to cope with them, and show signs of hope and motivation to realize new future plans which are in line with their capacities. Contrary to the literature, we found no evidence of self-stigmatization and demoralization. We therefore feel affirmed in our view that participating in photo groups can help patients to get along with their life and make it more bearable.

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Figure 1: Photograph of Dirk: “An empty terrace. When I hear voices (hallucinate) then I can’t sit among other people, because I speak with my voices.”

Dimensions of SIP	Inpatients	Outpatients	Total	Inpatients	Outpatients	Total	Inpatients	Outpatients
	T1	T1	T1	T2	T2	T2	T3	T3
	N=32	N=42	N=74	N=34	N=13	N=47	N=22	N=26
	Mean (CI)							
Somatic autonomy	0,63 (0-2,04)	0,71 (0-2,38)	0,68 (0-2,23)	0,88 (0-2,27)	0,08 (0-0,36)	0,66 (0-1,90)	0,86 (0-2,25)	0,31 (0-1,10)
Motor control	1,84 (0-4,37)	1,10 (0-3,45)	1,42 (0-3,89)	1,71 (0-4,64)	0,54 (0-1,74)	1,38 (0-3,99)	2,14 (0-4,92)	1,04 (0-3,09)
Psychological autonomy	3,09 (0,46-5,72)	3,12 (0,35-5,89)	3,11 (0,42-5,80)	3,21 (0,44-5,98)	2,46 (0,09-4,83)	3,00 (0,34-5,66)	2,50 (0-5,20)	2,19 (0,23-4,15)
Social behaviour *	4,47 (1,52-7,42)	4,57 (1,21-7,93)	4,53 (1,36-7,70)	4,26 (0,99-7,53)	2,92 (0,11-5,73)	3,89 (0,71-7,07)	4,68 (1,25-8,12)	2,65 (0-5,72)
Emotional stability	1,63 (0,13-3,13)	1,14 (0-2,55)	1,35 (0-2,81)	1,38 (0-2,80)	1,15 (0,01-2,29)	1,32 (0-2,66)	1,09 (0-2,36)	0,81 (0-1,91)
Mobility range **	1,50 (0,02-2,98)	1,38 (0-3,31)	1,43 (0-3,17)	1,44 (0-3,37)	1,15 (0-2,56)	1,36 (0-3,15)	0,86 (0-2,25)	0,92 (0-2,44)
SIP	13,16 (4,19-22,13)	12,02 (1,44-22,60)	12,51 (2,64-22,38)	12,88 (1,55-24,21)	8,31 (1,86-14,76)	11,62 (1,27-21,97)	12,14 (2,02-22,26)	7,92 (0-16,02)

* P < 0,05

** P < 0,05

Table 1: Scores for the Sickness Impact Profile Questionnaire (SIP) in a pre-and posttestdesign

Table 2: frequency, average age, sexe ratio and diagnoses according to residence status in patients included at the start of the study. N=74

<i>Variables</i>	Acute and short stay	<i>Long stay</i>	<i>Total inpatients</i>	outpatients	Total
Number	9	23	32	42	74
Average (mean)_age	35 Range: 28-47	45 Range: 27-66	42 Range: 27-66	42 Range: 18-80	Av. age 40
Male	3	11	14	15	29
female	6	12	18	27	45
Main diagnosis: schizophrenia related	6	12	18	12	30
Main diagnosis: mood disturbances	0	2	3	5	8
Main diagnosis: personality problems	2	0	2	4	6
Diagnosis: other	1	8	9	16	25
Missing diagnoses	0	1	1	4	5

Table 3: number of cases reflecting changes in the perception of the impact of illness at T3 (N=45) compared with T1

perception	mobility range	overall SIP
reduction in impact	9	5
same level	32	36
increase in impact	4	4

Table 4: division of selected cases in a sample (N=8) of long stay patients.

<u>Perception of impact of illness</u>	
reduction in impact:	2
increase in impact:	2
same level:	4

Chapter 6: The Photo-Instrument as a Health Care Intervention

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Abstract

Aims and objectives. The aim of this study is to describe how hermeneutic photography and one application of hermeneutic photography in particular, namely the photo-instrument, can be used as a health care intervention that fosters meaning (re-)construction of mental illness experiences.

Background. Studies into the ways how patients construct meaning in illness narratives indicate that aesthetic expressions of experiences may play an important role in meaning making and sharing. The study is part of a larger research project devoted to understanding the photostories that result from groups of psychiatric patients using the photo-instrument.

Design. Within a focused ethnography approach we employed a qualitative design of a single case study.

Methods. Text analysis of photostories was combined with observational data. Data were analyzed using hermeneutic theory. Participant observations were used for triangulation and complementarity.

Results. The interaction and collaboration between health care professionals and patients in the context of a photo group emerged as core concept that underlies the photo-instrument. The interaction triggered a reframing of meaning in the patient's illness narrative that offered new perspectives on positive identity growth. The role of visualizing meaning in images was found to lend a dynamic power to the process and triggered a dialectic between real life circumstances and imagination played out in the context of situated action.

Conclusions. The findings suggest that a positive reframing of meaning in illness narratives is facilitated by the photo-instrument.

Keywords: hermeneutics, mental health and illness; rehabilitation; recovery; research, qualitative

INTRODUCTION

Illness does not only influence a person's physical well-being and psycho-social functioning, but also affects and permeates the way how we experience ourselves (Kleinman, 1988; Frank, 1998; Gergen, 1994; Bury, 1982). Serious illness, especially chronic illness, transfers a patient into another life world with particular social roles, rules and identities (Kleinman, 1981). How a patient feels and defines his or her identity depends on the recognition one receives in the interaction with others (e.g. Gergen, 1994). In this process the patient must find answers to questions: 'Why me? What is the cause of my falling ill? How can I control the illness?' This involves coming to terms with experiences of loss, overcoming fear and anger and restoring self-confidence.

This adaptation to one's illness is done by ordering illness experiences in a personal story that accounts for the onset, continuation and exacerbation or possible recovery of illness symptoms over the course of time. Patient may use plot lines, metaphores and other rhetorical devices present in narratives to find coherence and meaning in the illness, and rework a life story in the light of illness or their recovery from illness. The moral meaning of these illness narratives consists in how patients struggle for authorship over their lives. This struggle is symbolized in one's personal narrative (author et al., 2010), reflecting (in the absence of exacerbation or remission of

symptoms) quiescence and homeostasis or an enhanced sense of self-efficacy and rekindled aspiration (Kleinman, 1988; Sitvast et al., 2010).

The telling of a story is also an event that is situated in social interaction (Bauman, 1986; Gergen, 1994). This applies also to the stories patients tell to health care professionals. In order to be more than a source of information useful for assessment, diagnosis and intervention, there must be a mutual knowing that acknowledges the subjectivity of stories as someone's truth at that moment (Frank, 1998). In the context of professional-patient interaction an open non-judgmental exchange of information is wanted, "where meanings are attained through mutual intersubjectivity rather than hierarchical levels of understanding" (Bowers & Moore, 1997, p.72; Canales, 1997; Wiltshire, 1995). This implies listening and an honouring of the suffering.

Stories may need no change, but one can nevertheless see that change occurs as the opportunity of telling one's story often offers a critical distance that is necessary for reflection (Benner, 2000; Frank, 1998). When health care professionals recognize and affirm this to their patients, then they communicate a message that their stories need not be trapped within fatality but are open to change. Through narrative interventions of this kind professionals may develop a relational narrative that focuses on dialogue (Gadow, 1999; Sakalys, 2000; Benner, 2000) and a co-construction of a joint narrative. The dialogue that holds a central position in a relational narrative helps restoring the agency of ill persons as capable, self-defining authors and allows for a movement toward a self with possibilities (Sandelowski, 1994). This is the emancipatory potential of relational narratives.

Narrative is a means of transforming private experiences into language and involves cognitive functions as perception and recollection. It is well known that mental images or pictures play an important role in verbal expression and recall from memory

(e.g. Smith & Magee, 1980; Nelson, 1979 cited with Rubin & Greenberg, 2003; Paivio, 1972). Metaphors are the most important form of imagery. They trigger a process of creative imagination that widens the horizon of the person who uses them (Ricoeur, 2003), freeing him or her from the mere facts available from the narrated event. Other notions can then enter the process of meaning making, as for instance anticipations of a willed future. Ricoeur (1981) used the concept of mimesis to describe how meaning in text becomes interpreted through metaphorical transformation (author et al., 2008). Mimesis is a philosophical concept from classical philosophers like Aristotle and Plato. Ricoeur interpreted it as a mental process that takes place during telling a narrative in which we reflect on lived experiences. We then go through stages of distancing our direct life experiences, reflecting on them from other angles ('widening horizons') which then leads to a reformulation of lived experiences. In this reformulation metaphors and imagery play an important role. They mediate how new meanings come about. By means of metaphors we apprehend one kind of thing in terms of another, setting the imagination free to integrate memories, anticipations and wishes into images that are charged with symbolic associations. For instance, when suffering from a chronic illness comparing our body with a motor that sometimes falters (but then can be repaired) may be helpful to invoke an image and voice a perception of realities and inequities of a life with pain that is less threatening than the idea of an unremediable illness and a body that betrays us in an unpredictable way. The imagery of a mechanical device may help the narrator to open up to a differentiation between pain and suffering, making a distinction between who we are and the inflictions that beset us (see also Frank, 1995; Scarry, 1985). In this way the metaphorical transformation of meaning that we endow to our lived experiences may help us in restoring to us the idea that we are to some degree the agents of our own lives. It reduces the suffering that comes from

experiencing powerlessness in the face of illness and pain. From *being* a patient one may become a person *with* a chronic illness. Having an illness needs not preclude someone to have goals, strivings and ambitions. To say 'I am' is to say 'I want, I move, I do' (Ricoeur, 1992). The notion of action is important here. When, because of illness and pain, someone becomes the *patient* of actions by others (versus being an *agent* of one's actions), this may be felt as suffering.

Mimesis is the process we go through as narrator of stories but also as we read or hear stories. We actively assimilate stories and integrate them into our life world. The way a reader understands a story and its plot may very well differ from the intentions of the author. We read the text from our own background and apply it to our own situation.

When patients are invited to picture a private experience, either by visualization or making real pictures, and narrate what they have viewed or depicted, then sensory images become iconized with meaning (Stuhlmiller & Thorsen, 1997; Gaydos, 2005). Through a process of association and projection images are charged with value-laden impressions, feelings, memories and anticipations. They then become the vehicle or carrier of content, just as is the case with religious icons which are invested with devotion. This finding of a carrier for sometimes diffuse sensations and impressions from lived experiences that are often difficult to verbalize is a first step toward integration into more complex meaning aggregates. Intertwining picturing and narration in therapeutic settings reflects the dialectic played out in the natural context of situated action. When the picturing is done with photographs that are used for eliciting narrative, then we speak of hermeneutic photography. The scope for hermeneutic enquiry in general is the way *how* meaning is constructed and integrated within existing

knowledge. In the context of health care we focus on how patients rework sensory perceptions in lived experiences from a level of mere 'sensations' into more contemplated thoughts and insights into the experience. Symbolization plays an important role in this process, often through the use of metaphors (see above). However, besides language other forms of symbolization of lived experiences are possible, e.g. visual images (photographs).

The purpose of this article is to explore the potential of hermeneutic photography within health care.

BACKGROUND

Photo-elicitation

The use of photography as an instrument of research has a long tradition in social science. It's been used and is still used as a data collection method (Banks, 2001; Emmison & Smith, 2000). Photos are shown to respondents to elicit information on key topics. This is called photo-interviewing. It is based on the principle that photographs provoke (elicit) a response: photo-elicitation (Harper, 2002).

More recently another form of photo-interviewing came up, namely autodiving. The photographs are taken by the interviewees themselves. The photos are then used in photo-elicitation sessions (Heisley & Levy, 1991; Joanou, 2009). There is a shift in the role of the informant and researcher: the informant has more voice in the choice of topics that are discussed and can do so with more authority because he has made the photo and can claim exclusive expertise.

Photo-elicitation in Health Care

As an instrument for research, photo-interviewing has also been introduced in medical and nursing disciplines (Hagedorn, 1996; 2002; Radley & Taylor, 2003; Riley &

Manias, 2003; Weiser, 1993). Bultemeier (1997), for instance, used photography as a way to inquire into the lived experiences of women with premenstrual syndrome. Drawing inspiration from psychological tests that use ambiguous images and photos to make subjects project their own interpretation into the test material, photo-elicitation is considered by some social scientists as a hermeneutical device (Hagedorn, 1996) that helps subjects to project meaning (Harper, 2002; Zaltman, 2003) from deeper layers of consciousness. In health care, Frith and Harcourt (2007) used hermeneutic photography to capture women's experiences of chemotherapy for breast cancer. Keller, Fleury, Perez, Ainsworth and Vaughan (2008) used a hermeneutic method with photography to uncover contexts relevant for assessing dietary intake and physical activity in diverse ethnic groups. Oliffe and Bottorff (2007) interviewed patients with prostate cancer on the photographs they had made about the experience of having cancer. Photography has also been used as a client-controlled instrument to improve quality of care (Royers, 2000). Although these examples of photo-interviewing focused on clients' reflections on their lived experiences, this was not done for therapeutic reasons. Photo-interviewing was in the first place a research tool; the reflection was not sought for as an instrument of improving awareness for the sake of empowerment. Photo research remained descriptive; it did not serve as a vehicle for transforming social reality.

Consciousness Raising and Empowerment

Some studies, however, do reflect a more explicit therapeutic use of photography. These studies often engage photography in an educational sense or as a means for consciousness raising and psychotherapeutic work (Bach, 2007; Berman et al., 2001; Hagedorn, 1996; Spence, 1984). As an intervention in institutional care this intervention is still relatively unknown (Riley & Manias, 2003). Radley and Taylor (2003) are among

the very few who used photography in a hospital setting to have patients reflect on their hospital stay.

Wang and Burris (1997) provide a clear example of how photo-elicitation can be combined with the agenda of empowerment, in a collective way rather than fostering individual empowerment. Participants in their study made a set of photos depicting day-to-day routines and events. They were then asked to talk about their lives as depicted in the photos. Being grounded in real experiences, the photos triggered authentic stories. The technique was used for working with underprivileged and marginalized groups. Wang and Burris, for instance, applied photography as a means to educate Chinese women and support social action. Using photography in this sense works two ways: it validates and empowers the subjective experiences of these groups and it is a means of communicating needs, concerns and priorities to policy makers, health officials and others. Wang and Burris stressed the importance of giving voice to people who otherwise may not be heard because they lack the power, the money or the status to make themselves heard. Therefore, they called the approach 'photovoice'.

Hermeneutic photography and the photo-instrument

Hermeneutic photography as a therapeutic instrument aims at facilitating persons to give meaning to their life world. Photographs enable humans to find meaning through visualizing and interpreting lived experience. Making photographs of situations in one's life may be seen to trigger a reflective process in which images become the carriers of symbolic and metaphoric associations, of which the photographer had no clear idea when taking his pictures (Hagedorn, 1996). The idea that photographs produce images of real life invites action oriented associations, that can be connected with an agenda of

empowerment by focusing photographs on wishes and ambitions, as was done in the photo-instrument.

We consider the photo-instrument an applied form of hermeneutic photography. Group sessions were organized with patients who were invited to endow meaning to pictures made with a disposable camera. Nurses and occupational therapists conducting the photo groups fostered the process of elicitation among participants (see also Sitvast et al., 2008). The photo groups followed a protocol developed and tested by the first author in an earlier phase of the study (Sitvast, 2004). Clients make photographs, talk about them in group meetings and exhibit their photo stories to a wider audience. The broader intention of the intervention is connecting clients with sources of individual strength, thus helping them to empower them. Reflection and dialogue are essential elements in the intervention. In the intervention the dialogue between nurse facilitators and group members is a reiterating process going on during all sessions.

The photo-instrument we applied resembles the photovoice approach of Wang and Burris. Our instrument differs, however, from photovoice in its focus on the individual process of meaning making as compared to its use for research, education, social change and public health (McNamara, 2009).

METHOD

Setting

Our hermeneutic photography intervention was part of a larger research project devoted to understanding the photostories that result from groups of psychiatric patients using the photo-instrument. Settings varied from a (medium-) long stay treatment ward in a psychiatric hospital, to a daytime treatment centre, and three sheltered homes. During 2005-2009 sixteen photo groups were organized (with a total of 74 participants). The

criterion for inclusion in the study was recovering from a psychiatric crisis and not being severely limited by psychiatric symptoms. Beyond this criterion participants reflected an average sample of patient population when considering age, residence status (inpatients-outpatients) and diagnosis cluster (table1).

INSERT TABLE 1

Design

The overall approach of the larger research project is focused ethnography. Focused ethnography differs from the classical ethnography. Other than in classical ethnography the location may be a treatment site (such as a clinic) rather than a place of residence.

“Participants may not be connected by the same culture (in its broadest sense), but share behavioural norms and a common language emanating from experiencing a common illness. Participant observation is limited to particular events or times, and interviews are generally limited to the selected topic and surrounding event.”(Morse & Field, 1996).

We considered participants of the photogroup as belonging to the same group, sharing the same experiences of being a psychiatric patient and going through a phase of resocialisation or rehabilitation. In nine photogroups (intotal forty-seven participants) the researcher (first author) participated in the group sessions and made observations that together with other data contributed to the construction of cases. Cases are constructed on the basis of the trajectory that participants passed through while participating in the photogroup. The overall study follows a multiple case design.

This detail study is an single case study providing an insight into the issue what role health care professionals can play in facilitating the process of meaning (re-) construction by patients in a mental health care setting. Focusing mainly on “what” questions, a exploratory case study was called for (Yin 1994). The case was selected based on the criterion of its learning potential; it contained rich data that demonstrate

how the process of meaning making develops in an intricate and subtle interaction between the facilitator (health care professional), the participant and the context of representation.

Data Collection

We collected the photographs and photo stories as told by the patient in the selected case. These photo stories were expressed in the series of meetings of the photo group (two rounds of eight sessions of 90 minutes). Besides collecting data from photo stories the first author did participant observations of these meetings and recorded them in field notes, whereas the care professional who facilitated the group filled out observation forms after every session. The data were considered to be a complementary dataset that gave us information on the contextuality of photo stories.

Analysis

The meaning of photographs arises in a narrative context (Cronin, 1998). As we assume that the function of photographs is primarily the creation and maintenance of meaning, we decided for a hermeneutic analysis. We analysed text on three levels: the intra-textual level of the narrative, the interactional level that serves the communication with other people and the meta level of representation (Van Leeuwen, 2001) where the moral issue of agency and authorship is at stake. For the interactional and meta level of representation we leaned heavily on complementary data from observations and field notes.

In the hermeneutic analysis we looked at structural elements, of which the plotline of the narrative was seen as most important. The evaluative direction of the plot (progressive, regressive) was interpreted as indication for how the participant gave

meaning to his suffering. Besides progressive and regressive plots we distinguished a consolidation or stability in a narrated life (Gergen, 2001). On the interactional level we analyzed how a story served certain relational functions. On a meta level of representation we analysed how someone presented himself as a moral agent. For all three levels we considered how the care professional who facilitated the group influenced choices that were made by the participant.

Validity and reliability

“Cameras do not take photographs, people do”, (Beyers cited in Prosser & Schwartz, 1998, p. 125). In hermeneutic photography this means that research participants make their own photographs and do their own interpretation. Photographs are always made in a certain context that partially lends them their meaning. We cannot detach this context from the interpretation. To meet demands of plausibility and believability, the researcher must therefore offer “full contextual detail”(Prosser & Schwartz, 1998, p. 125), meaning a detailed account of both the external and internal photo context (Banks, 2007). The external context is, for instance, the micro context of the photo group. Sharing the photography experience with other people may influence the choice of photographs and the story you tell. So may the fact that you are a user of psychiatric services. The researcher must therefore have an open view to photographs that are disqualified, “silent stories” that are not voiced. He must pay attention to group dynamics and other forces that urge for conformity when participants perform as photographers and give a representation of their life world. The researcher needs to be reflexive. By giving reflexive accounts the researcher renders explicit the process by which data and findings were produced, thus creating plausibility and believability. Triangulation of methods enabled the team to cover a rich variety of perspectives.

Ethical considerations

The study was executed in accordance with the norms and regulations under Dutch legislation on medical research (the WMO-Law) and was approved by the appropriate Medical-Ethical Board. A proper informed-consent procedure was part of the research protocol.

The patient whose case we used in this paper, was asked explicit consent for allowing us to publish his photos and his story, after informing him on the implications of his decision.

RESULTS

Experiences from practice: the case of Boris

We will now illustrate how hermeneutic photography, in casu the photo-instrument, facilitates meaning (re-)construction with details from one case. Boris is a 49 year old man, vulnerable for psychotic decompensation and depression. He has been married, but his wife divorced him. He has two children who still live with his wife. He regularly visits them. At the time of his participation in the photo group, he has been living in a sheltered home for six months. He has had some problems with his weight, for which he consulted a dietician. In response to the photography assignment to make pictures of things and persons that were dear to him or that he valued highly, he photographed, among other things, his scooter.

INSERT FIGURE 1

Figure 1: the scooter

What did he tell about this photograph? The scooter meant for him that he could go and visit his ex-wife and his teenager children whenever he wanted. He commented on his photographs of his scooter as follows: “This is a fine picture of my scooter. It looks like a motor-cycle . . . It gives me a feeling of freedom and openness when I ride and feel the wind.” This is a statement that conforms to cultural and social accepted ways of expressing freedom, but there is a curious twist that turns his feelings toward experiences of loss:

“It is an artful machine. It runs and does not falter; it is mechanical. Me, I am not like that. I have no skills. Yes, I had at one time when making videos of weddings. I did the video-making when things were still okay with me. Shooting film all day long, that’s what I liked to do and wedding couples were always contented with the result. You know, I’m also good at . . . smoking.”

This part of his story reflected Boris’ powerlessness facing the problems in his life before he moved to the sheltered home. Lacking skills for self-maintenance, he had become depressed and had slipped in self-neglect. Now he was on the road back again. There is a close interplay of reality and representation in Boris’ story that called for a reflexive reading of text (Walsh, cited in Pink, 2007, p. 23-24). This implied also checking how his mentor nurse looked upon his functioning and how she interpreted his agency. All these observations came together and were related to an analysis of how his story fitted his autobiography and was congruent with actual choices and challenges Boris was facing.

A first series of 8 sessions is followed up by a second one, focusing on photographing a goal or wish that participants wanted to realize. Boris selected five

photographs that formed the backbone of a photo story. We will provide excerpts from his story.

INSERT FIGURE 2-6

- [two pairs of trousers with different sizes on a drying mill] : “Losing weight is important. I’m too heavy now. A better physical condition is healthy. Now I’m tired every time I do something. I think it is hard to lose weight.”
- [Martha, the group facilitator pushing him]: “I need help to lose weight. I move too little. I think it is not that easy and I am not motivated.”
- [sausages on a cooking-range]:
“Nice sausages on the roaster. I love them, but I can’t have too much of them. Actually I don’t eat that much. But if I like something, I eat more. When I look at the picture I’m getting a bit peckish. The smell and the taste of the sausages [trigger me]. I’ve been to the dietician for it. She couldn’t help me. If I eat less, I keep being hungry. It affects how I feel.”
- [Boris on a bike]: “Biking would be a challenge. They tell me to go biking, but it’s up to me to actually do it. If I want to lose weight then I have to. Maybe a tandem bike is a good idea. Then I don’t have to bike on my own.”
- [Boris and his dog]:
“Max is my resource (referring to the assignment that instructed participants to also photograph their resources that supported them). He makes me walk much further than I otherwise would do. Max walks alongside me and together we take a break every now and then, when he wants to pee.”

Analysis

We analysed Boris' second series of photographs in relation to what he told us and the observations of the nurse and the researcher. The images were clearly premeditated to match his point of view: how difficult it is to lose weight, and that one is dependent on others to realize such aim. Together with what Boris told us the five pictures made a coherent story. The story had no clear perspective. There is no progressive or regressive outcome, whereas consolidation or stability is also not at stake.

A further narrative analysis however makes clear that the story serves as an excuse for Boris. It explains why it so difficult to lose weight. It does so in a lightly ironical style, that makes Boris sympathetic to us. The big-sized trousers next to the smaller sized trousers: the image has a touch of pathos to it. The point of his story seems to be: I 'm so eager to lose weight, but I can't do it; I need help. At the same time the text breathes aloofness and a kind of self-consciousness. He uses the I-form: "I have been to the dietician. This didn't help me." There is no self-victimization. Sitting on his bike he looks at us and smiles, enjoying the attention in a sphere of self-irony. There is an undertone of feeling impotent to do something about his problem, but also a strong wish not to let this feeling dominate his life too much. His pictures and texts convey this in a strong way, for instance: the image of the dachshund Max, trotting down the street on his little paws and drawing Boris along. Boris plays trumps with a skilful use of a cultural repertoire of irony.

We noted that Boris used humour as a defence mechanism against too much confrontation with his limitations, but nevertheless his texts came to show him as vulnerable and open in the course of time. From observations and what he said about this himself we recognized that Boris came to experience the group as a safe haven that helped him to let go his earlier reticence. Eventually he performed the assignment in a

playful way. He enjoyed the attention from others, for instance when Martha (the care professional) gave some logistic support in the making of some photographs (as we can see in the photograph where she pushes him).

We first considered how the photographs were made. The fact that the photographs are staged and are taken within the enclosed space of the sheltered home is of importance, as well as Boris figuring himself as central subject. There is a certain self-consciousness that speaks from the images themselves. For instance, Boris sitting on a bicycle demonstrates his wish to engage in more physical activities. There are unintentional symbolical overtones where the bicycle stands for setting his life again in motion and also: taking the road, heading for change versus stagnation. The photograph of the two pairs of trousers is at first sight indexical: the picture denotes that losing weight means that he can put on trousers with a smaller size. The symbolism in this photograph is more implicit. In advertising people who have success in life are often portrayed as having a slim and slender figure. Images that show persons who are fat carry a connotation of indolence and being not so smart. Thus Boris' photograph may symbolically refer to his wish to belong to the group of people with success and participate in society. This may be considered a silent story that Boris could not voice.

How did Boris present himself with his photographs and what image of himself did he bring across? Did shame or shyness refrain him from an eloquent presentation? Did he feel anxious about his photographs: sometimes people feel unsure whether their pictures are good enough in a technical sense or feel ashamed to tell a personal story. From participant observations we recognized that at an earlier stage, when shooting the pictures, Boris had found it difficult to decide what to photograph and when, asked to select pictures that were most telling, he only chose the photographs about his struggle

to lose weight after some hesitance. He speaks about his photographs in a laughing style as if he mocks himself. It seems as if he does not take himself too seriously. This might have to do, so we inferred from observation, with uneasiness in relating to group members or the nurse facilitator. It is also likely that talking about his body is an awkward thing for him to do. It touches on a taboo that many people (maybe men more than women) feel when the subject of their physical appearance comes up for discussion.

Boris' way of representing himself is an example of a rhetoric style in communication. The positive response from the other participants and the nurse helped Boris to maintain his integrity and put up a credible performance. Boris was acknowledged in his expertise of presenting a photographic report (reminiscent of wedding videos he used to make in an earlier phase in his life). He regained "face" as someone who could be respected for his skills. Where he voiced his dependency on others on certain occasions, his performance (his photographs more than his words) gave voice to a more resilient identity.

Boris' story matched real issues in his life. He developed his story from a station of powerlessness through self-irony into a more triumphant "I can!" He became an agent in his own right. Somewhere in this trajectory his readiness to really make a change was born. From observations by the health care professional we learned that his commitment was furthermore strengthened by the photo exhibition and the response from his family and fellow inhabitants of the sheltered home where he lived. He took up biking with his mentor nurse. Six months later he had lost more than 20 kilos in weight. He was extremely proud of this.

How the health care professional facilitated meaning (re-)construction

Co-construction

Until now we focused on the way in which Boris expressed and presented his photo story. But how were his images and the accompanying text produced in the first place? The group facilitator knew that Boris had consulted a dietician and that he wanted to lose weight. When Boris pondered over the assignment to take photographs of a wish that he wanted to realize, she suggested him to take this as theme for his photo story. He agreed and set about taking photographs. After failing a first effort to make the photograph with the trousers as he had planned it, she offered him assistance. At first he declined the offer, but later he accepted her help. Boris told his story in a series of sessions, during which the group facilitator triggered him by questions and feedback to elaborate his story step by step until he felt safe to present it as an “official” text for the photo-exhibition.

Thus, Boris’ photo story has been co-constructed with Martha right from the beginning. This is part of the external narrative (Banks, 2007) that determines the context of Boris’ photo story. Photographs are not only made based on an assignment that frames their subject or theme, but also, in Boris’ case, with the aid of the care professional conducting the group.

Photo-elicitation

Another element in the external narrative is the way in which meaning making depends on the interview technique that is called photo-elicitation. Photo-elicitation uses photographs to invoke comments, memory and discussion in the course of a semistructured interview (Banks, 2007). By using photographs made by the respondents themselves the more formal aspects of interviewing can be avoided and the succeeding reflection on one’s own photographs approaches a more intimate context that resembles a natural exchange over family snapshots. We have observed how this was the case with

Boris and his fellow group members. There was an atmosphere of pleasantness and openness that helped Boris to make further steps. Photo stories are shared with others and there may be a tendency for photo stories to converge to common themes that are shared with other group members. Medication draining your energy was a theme that Boris said he recognized in someone else's story. At the same time the group context may refrain individuals from giving a too personal account. In the case of Boris he admitted that at first he did not like it to recount in detail what his problems were with losing weight, but after overcoming his reticence he was very open about it.

Empowering Context

Hermeneutic photography is an example of how visual media can aid disempowered people in gaining greater control over their lives. The assignment focused on the formulation of a wish that one would want to realize. The representation of his wish to lose weight helped Boris to anchor this in mental icons that gave him the drive to actually realize his wish. The following observations, made by the first author, shows how the care professional who facilitated the photo group engaged in a conversation about Boris' photographs and helped Boris to widen his horizon (a hermeneutic aspect):

Martha (the care professional) asks Boris to tell more about the challenge there is in for him. It appeared that the dietician had advised him to engage in physical activities more often. Boris tells that his scooter is in repair and that he has a bike on loan. "Aha", Martha says, "maybe you can bike then!" Boris' response is somewhat giggly and he says that it is not very likely that he will do that. "Maybe you need a little push, as you suggested on this picture?" Martha answers and she continues with: "When you do move, what then triggers you?" Boris answers that he likes walking with his dog. "That is fun." Martha takes up the cue and asks Boris: "What is necessary to make biking also

fun? Maybe if you go biking together? Must someone ask you along?” She challenges him to go biking with her next week. Boris laughs and leaves it open whether he will do that (research field notes).

Left alone to make his own choice (without Martha entering on a dialogue with him), Boris would probably have taken other photographs or would have selected other photographs to relate to. But considering Boris’ story as not merely a mental representation, but as an enacted story that is part of performed social behavior, we think that this “collaboration” is indispensable.

Empowerment can be defined as a process in which “the client or community takes control over the change process, determining both the goals of this process and the means to use”(Tengland, 2008, p.77). It may seem contradictory that a professional plays such an important role in taking control by stimulating the client as Martha does, but then we must realize that the approach aims at decreasing her own control and facilitating a process of change. The professional acted here as a facilitator and a process-expert (Tengland, 2008). Furthermore, working with photographs can be compared with applied arts and artwork in the performing arts and just like them invites audience and participants to partake in “a conversation with myriad meanings, interpretations and points of view”(Sanchez-Camus, 2009, p. 349). ‘Audience’ may be identified as the client himself where (s)he becomes involved in the dynamics of being a spectator not only to the photographs of fellow participants but also to his/her own photographs. The role of the facilitator is also to engage the participants in this dialogue and exchange, as Martha obviously did. It is here that ‘the discourse itself becomes the active generative process’ (Sanchez-Camus, 2009, p. 349).

From practice to theory

Reflecting on experiences from practice in the case of Boris we were able to identify the steps or actions the care professional had to take in facilitating Boris to present his story in a meaningful way. We present these steps here as operationalisations of two central concepts that we deduced from the theoretical framework that underlies hermeneutic photography: mimesis and performance (Sitvast et al., 2008).

Mimesis concerns the process of meaning (re-) construction and involves the content (the narrated event). Performance is the story-telling as a mode of communication (narrating event).

INSERT TABLE 2

DISCUSSION

The case we presented is the unique story of one human being. We cannot expect that every run of the intervention will result in similar outcomes. Generalization to population was not our aim. Presenting the case of Boris we were able to find patterns in the actions that health care professionals undertake when applying the photo-instrument. We do think that application of the steps we described make it likely that some form of positive growth in identity will occur and that this is sometimes the first onset of greater changes. Limitations of our study are that we restricted participation to patients who were stable enough to look upon their lives without greatly risking exacerbation of their psychiatric symptoms. Also patients with acute psychotic symptoms were not included. They lacked the communicative powers to profit from a group approach. Patients with

deep depressions were found to engage in and ruminate too much over experiences of losses. They too were excluded from participation.

We think that the mixture of hermeneutic actions, group dynamic interventions and the aesthetic dimension of expression in images combines three professional agendas. With the photo-instrument health care professionals facilitate a process of meaning reconstruction that is set in an practical agenda of goal finding and generation of hope (1). The sensory impact of images in a photo story matches the life world focus of many health care professions, e.g. nursing (2). The visual representation facilitates a representation of patients as moral agents, which serves the empowerment of patients and reduction of their suffering from illness and disorders (3). These professional agendas have also been integrated in psychiatric rehabilitation and especially its recovery-oriented update of recent years. Connecting the photo-instrument with recovery-oriented support, the photo-instrument becomes a tool in the toolbox of health care professional working in mental health.

Health care professionals need no other skills to facilitate a photo-group than a certain proficiency in guiding a group and a sensitivity for how to respond to patients' narratives, entering in a dialogue and creating a relational narrative together with the patient. A certain flexibility is demanded to suspend the so-called 'reparation-reflex', that is the nurses' and other professional caretakers' inclination to diagnose a deficit and respond to someone's story from a interventionist perspective.

CONCLUSION

The findings suggest that a positive reframing of meaning in illness narratives is facilitated by the photo-instrument. The interaction and collaboration between the health care professional who guided the photo group and the patients was found to facilitate a

narrative process that culminated in a representation of Boris of assumedly more authentic aspects of his identity. Although this was an one time performance in the context of the photo group we think that the occasion offered him a learning experience from which Boris may profit in a further process of personal growth. Grounded in the case we identified actions health care professionals need to take in order to foster reconstruction of meaning in a relational context of empowerment. These include among others the elicitation of meaning, prolonged dialogue, focussing attention, anchoring and organization of a photo exhibition.

CONFLICT OF INTEREST

No potential conflict of interests is disclosed by the authors.

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Table 1: frequency, average age, sexe ratio and diagnoses according to residence status in patients included at the start of the study. N=74

<i>Variables</i>	Acute and short stay	<i>Long stay</i>	<i>Total inpatients</i>	outpatients	Total
Number	9	23	32	42	74
Average age	35	45	42	42	Av.age 40
Male	3	11	14	15	29
female	6	12	18	27	45
Main diagnosis: schizophrenia related	6	12	18	12	30
Main diagnosis: mood disturbances	0	2	3	5	8
Main diagnosis: personality problems	2	0	2	4	6
Diagnosis: other	1	8	9	16	25
Missing diagnoses	0	1	1	4	5

Table 2: core concepts of the photo-instrument operationalized into methodological steps (actions) and illustrated with examples from the case of Boris.

Actions	Examples in the case of Boris
<i>Mimesis</i>	
Photo-elicitation	The nurse asked Boris what the scooter on his photograph meant to him.
Probing	The nurse tries to surface deeper layers of meaning by asking what challenge there is in for him when he mentions the issue of losing weight.
Prolongued dialogue	The nurse engages in a dialogue with Boris over his wish and how to realize it that extends itself over several sessions. In this way the fluidity of narrative truth and its changeability is emphasized.
Re-iterant testing of text	Boris got the opportunity to adjust his texts where he was asked to select photographs and text for the photo-exhibition, thus to integrate his newly developed understanding that losing weight was after all possible.

Focusing of attention	The assignment to photograph a wish and also how one would realize this wish focused Boris on his issue. So did the instruction to group photographs together and paste a memosticker to every group with a label that described the group. There is a continuous process of selecting and prioritizing of photographs and text.
Anchoring	The nurse steered Boris toward concrete actions and a realistic scenario. She helped him to anchor his photo story in his actual life world.
Bridging of contexts	The nurse stimulated Boris to look beyond a more restricted version of his story that focused on his being unable to follow up the dietician's advice.
<i>Performance</i>	
Holding and containment	The dosed and structured way helped Boris to overcome his initial reticence. The nurse emphasized the need for confidentiality of everything that participants told during sessions. Discussing the impact of his photo story on invited guests of the exhibition the nurse helped Boris to feel responsible for exposing certain traits of himself and also to draw the line at a point beyond he wanted to keep things for himself.
Organisation of a Photo-exhibition	Sharing his photo story with others at the photo-exhibition was another means of committing Boris to his agenda of changing his life style. At the same time it gave him an opportunity to present himself as an agent of his own life. We observed how his face shone at the opening night of the exhibition when he showed around his wife and children.
Exchange of text in a peer group	The nurse stimulated listening to the stories of others and invited everyone to respond to each other with positive feedback. Within-group comparison of stories contributed to a more realistic attuning or to a recognizing of potential obstacles, as was the case when Boris learned from others how medication may drain your energy. Discussing these issues with the group the nurse fostered more openness.
Anticipation of future action	The nurse challenged Boris to break out of his fixation on disempowering feelings from the past and present. The opportunity to first imagine possible future actions and then make it visible mentalizes action schemes and works as a kind of virtual simulation.

Discussion

Introduction

We will now return to the research questions to see whether we can formulate overall conclusions that tie the findings of our study together and connect them with issues in health care and nursing, especially in the area of recovery. Traditionally, within the discipline of nursing existential questions and meaning making have always gained a lot of attention. Nursing theories, such as those of Holland, Grypdonck and Tronto, reflect this philosophical attention for patients' needs beyond the mere physical and socio-psychological aspects of illness. Nursing entails helping the patient to make sense of the illness and its meaning in the context of his life, and is more than just formulating a diagnosis and giving a proper treatment. Within nursing it is emphasized that caring *for* a patient is connected with a caring *about* (having concern for) someone's needs (Tronto, 1993). This care-ethical principle underlies our ambition to develop a more narrative-based nursing that could contribute to the recovery of patients. Our study is thus closely related to these nursing scholars, but goes a step further as it integrates theory and practice.

Research questions

Our general aim was to examine how nurses can use photography to assist patients in making meaning of experiences of illness and help them in their process of recovery, which can be considered an important contribution to good care in the professional context of nursing. We formulated four sub questions to answer the overall question:

1. How can the process of meaning making be conceptualized based on the work of the hermeneutic phenomenological philosopher Ricoeur?

2. How do patients in mental health care give meaning to their suffering with their photo stories?
3. What is the therapeutic role of the photo-instrument in the context of recovery?
4. What are the methodical implications for the application of the photo-instrument in the context of mental health care?

These four questions reflect a hermeneutic-phenomenological approach. This approach was chosen as our aim was to study how nursing can foster processes of meaning making in patients. Hermeneutics studies the way how people make meaning and phenomenology ties this study to actual phenomena and existential problems. We departed from an exploration of a theoretical framework grounded in hermeneutic philosophy of Ricoeur (first research question). We concentrated on two interrelated phenomena, namely the experience of suffering and caring as an answer to suffering. The theoretical framework provides the concepts to understand the processes of meaning making in practice. From there we focused on processes of meaning making from a more phenomenological perspective (second research question). We turned to the photo-instrument as a praxis in which photo-stories help patients to make sense of their suffering. Then we focused on the therapeutic implications (third research question) and lastly we studied the methodical implications for nurses and other health professionals (fourth research question).

We will now look into the four questions one by one.

1. How can the process of meaning making be conceptualized based on the work of the hermeneutic phenomenological philosopher Ricoeur?

The French philosopher Ricoeur (1913-2005) devoted his professional life to writing and teaching on answering a number of important questions that play a role in human interaction. The issues that he studied concern the relation between an individual's action and his agency, the role of the free will and how this relates to evil and wrongdoing and also how personhood and identity are connected with continuity through time that is set in an ethical and moral context. Ricoeur did not study these issues as big questions far from the everyday world, but as factors that can be seen at work in the practice of human interaction. The questions he therefore formulated to study what happens in communication were: who is speaking? Who is acting? Who is recounting about himself? Who is the moral subject of imputation? (Ricoeur, 1992). Ricoeur has unravelled these questions, making use of theories from diverse scientific disciplines, varying from philosophy to logical theory, pragmatics, semiotics and linguistics. His search resulted in a series of studies that have become classical works of philosophy in modern time. Especially '*The Rule of Metaphor. The creation of meaning in language*' (1977) and '*Time and Narrative*' (1984) are relevant for us, because these studies focus on processes of meaning making in the context of storytelling or narrative. In these key studies he developed a theory about how people make sense of their experiences in real life and attribute meaning to them by constructing a story. People tell stories or narratives² to reorganize disjointed bits of information in a new meaningful structure that has the following elements (Burke, 1945): the action of the story (the sequence of events), the scene (*where* and *when* did things happen), the agent (*who* did the action), agency (*how* did he or she do it) and the purpose (*why* did it happen). In constructing a story someone brings together these elements and relates them to each other in the plot

² The distinction that is sometimes made between 'narrative' and 'story' relates to types and degrees of internal structural organization but are not relevant here.

of the story. This is called the emplotment of a story. In 'The Rule of Metaphor' and 'Time and Narrative' Ricoeur wondered how this emplotment came about. According to Ricoeur emplotment is the outcome of a transformational process that he identified as 'mimesis'. He distinguishes several steps. First there are lived experiences of which someone feels the urge to get grip on them. However, this is hard when you are still immersed in the situation, for instance when you are a patient and live through the direct aftermath of a psychiatric crisis. That's when someone needs to create some distance between him and an overwhelming experience in order to be able to reflect on what has happened. When someone succeeds in finding the necessary distance then his position does not longer fully coincide with overwhelming events. A meta-position is created from where it is easier to open up to other meanings than seemed dictated by the facts of an experienced event. This is what Ricoeur called a widening of horizons. The process of mimesis is one in which past memories and anticipations (hopes, wishes, fears) of the future join the reflection of experiences in the present, in this way making possible a fuller and may-be more authentic (in terms of someone's history) account of what events mean to someone. What triggers this process is imagination: a creative play in which the mind juggles with associations and images. Ricoeur claimed that metaphors and imagery have a central role in this creative play. Metaphors are a figure of speech which transfers meaning from one domain to another, for instance from perception into cognition in 'I can see what you mean'. Imagery is the more general naming for figures of speech in which an image carries a connotated meaning, as for instance in 'Photographs are a vehicle of messages about oneself'. Metaphors and imagery enable someone to jump from one line of thought to another and in this way reformulate lived experiences. These reformulated experiences then condense in a narrative plot. What is of special interest in

the context of our thesis is the role of images in Ricoeur's concept of the mimetic process.

Ricoeur's theory enabled us to recognize phases in the patients' trajectory of meaning making: through distanciation of lived experiences to a condensation in a narrative plot. Pieter for instance (his cases has been described in chapter 3), one of our participants in the study, made a photograph of a mouldered elm ravaged by a storm and used it as a metaphor for what a psychosis had done to his mind. In this way he could reflect on his situation, rethinking where his position was in his contact with caregivers. According to Ricoeur, action, lived experience and its emplotment in stories are strongly interlinked. He focuses on textual aspects, neglecting performative aspects. We found that patients used their photographs not only as imagery, but also to situate their story in reality. Distanciation was often followed by a certain factuality, connecting patients again with concrete palpable reality. Images remained linked up with strong sensory perceptions. This gave stories a freshness and acuteness in communication, deriving from 'dense impressions', not fully accounted for by Ricoeur. He downplays the role of the image, because he claims that images can only become intelligible through interpretation in language. Our finding that images retain strong links with sensory perceptions enriches Ricoeur's theory, acknowledging that taking photographs is also a distanciating act, putting a camera between you and the perceived reality and that images as a result of this act invite further reflection. We described the sensory impact of images in terms of iconic quality. Like in religious icons, photographic images can be charged with associations and impressions that make sense of an experience, or in other words represent it.

We conclude that the concept of iconic representation, also embraced by Ricoeur, should not be restricted to verbal icons. The sensible, sensual plenitude that Ricoeur (1977) ascribes to poetry can also be found in sculpture and in photographs. In photographs too, we observed a fusion of sense and *sensa*: sounds, images and feelings, that does not only provide an occasion for an unfolding of the imagery, but also exerts a force in itself upon the world, including language (Goodman, cited with Ricoeur, 1977). This force is based on the principle of psychological association and is realized in the act of expression. In fact, the effort of expression evokes the psychic associations (Ullmann cited with Ricoeur, 1977) of lively impressions from memory and emotions that makes the image 'iconic'. This is the figurative ability of images, the potential of making-seen, the 'setting before the eyes'. In metaphor, the verbal moment and the non-verbal moment cooperate. As Ricoeur says, 'metaphor owes to this liaison its seemingly essential concreteness' (Ricoeur, 1977: 246). Ricoeur recognizes that images alone (apart from their functioning in metaphors), seem closed to themselves and stand for a sort of 'private' mental experience that impedes the mimetic process, the 'seeing as' that makes the sense and image hold together. On the basis of our findings however we think that the 'thingyness', the 'iconic solidity' of images, however self-contained it may be, lends a vividness to it, be it a metaphor or more concrete information about someone's life world, reifying it and making it more compelling and easier to remember. Ellen, for instance (her case has been described in chapter 2), photographed a lane in the wood that she already visited in her youth. The dark lane with light shining through the trees evoked strong emotions and associations with her course through life. In the image memories merged with anticipations and hope, which was mirrored in the alternation of light spots and dark corners. This is related to the domain of psychology and neurology, which we did not address in this thesis. Still, we may conclude that the iconic quality of

images is very important in the context of the nurse-patient relationship, because it grounds the communication between nurses and patients in the sensory lived-through experiences of the patient. Photo-stories protect nurses from a too rapid and premature thinking in actions and things to do. We did not research this specific aspect, but we assume that this effect is brought about by the density of meanings in certain photographs that possibly lends them an urgency that is sometimes lacking in 'ordinary' conversations between patients and nurses. These iconic photographs probably make a strong appeal on the viewer to further explore the condensed meanings with the patients who made them. They seem an entry for learning more about the identity of the patient. This also applies to the needs that flow from this identity. We think that iconic photographs facilitate recognizing someone's identity and his needs. If so, this is of imminent importance for certain basic competences of nurses. According to Tronto (1993), nurses need to be attentive and sensitive to patients' needs, combining a concern for someone with skilled expertise in order to realize good care. Attentiveness, that comes before the diagnostic process of assessing health problems, at a later stage enables responsiveness of care to the unique person and his particular needs. It takes into account the susceptibility of the patient for certain specific nursing interventions. In other words: does the nurse sense how a patient will receive and respond to care that she will give? In the rush of busy routines under time pressures that are always present, nurses tend to forego this process of tuning to the person of the patient and pass on to the pragmatics of daily care. We think that photographs invite the nurse to suspend acting from a problem-oriented way of working and that by sharing the meanings of a photograph they may come to know a patient better.

This connects the photo-instrument with the humanistic focus of psychiatric nursing (Travelbee, 1969), that since the sixties of the twentieth century inspired the emergence

of the therapeutic alliance as an important paradigm for interaction between nurses and patients. Therapeutic alliance has been overshadowed for some time by an emphasis on diagnostic rationalism in the wake of a tendency to mould nursing in the image of medicine, but today is back again in the centre of mental health nursing, for instance in the latest developments of psychiatric rehabilitation/ recovery (e.g. Wilken, 2001) and theories about person-centred care as for instance the Engagement approach (Bennington-Davies & Murphy, 2005). We may conclude that there is nothing new under the sun, when we realize that as far back as 1952 Peplau already emphasized the importance of interpersonal relations in nursing. In the Netherlands, to mention just a few nursing authors, Van de Brink-Tjebbes (1975) resisted the idea that nurses could detach themselves from the subjectivist perspective in favour of a objective inventory of problems in their patients' life and Van der Bruggen (1992) postulated the necessity of an existential analysis of life problems in his proposal to found an anthropologically-based nursing.

2. How do patients in mental health care give meaning to their suffering through storytelling?

An analysis of photo-stories revealed that in 27 out of the 42 cases patients mentioned their illness experiences explicitly and reflected on them. This leaves us fifteen participants who did not mention their illness experiences explicitly or only very briefly in their photo stories, focusing on other aspects of their lives. Since the assignment for making photographs focused on values and on what one holds dear we cannot conclude that all fifteen patients did not experience their suffering as being part of their lives.

Patients go through stages often in line with the phenomenological model on suffering that we derived from Eriksson (2006), and this suits our aim to discern the role of stories in suffering. Eriksson developed this model for broad groups of patients, not specifically for psychiatric patients. He distinguishes three stages in a climbing order. Patients can *have* suffering, *be* in suffering or *become* in suffering (Eriksson, 2006). To *have* suffering implies that the person will not acknowledge his suffering and will flee from it, trying to explain it away. To *be* in suffering implies that a person often experiences restlessness and may try to alleviate his suffering through the satisfaction of direct needs. When someone *becomes* in suffering someone engages in a struggle between good and evil, hope and hopelessness, between life and death. Passing through this struggle the person may continue towards a higher awareness and greater spiritual strength (Eriksson, 2006).

In our study we saw examples of how participants, passing through these stages, used their stories to connect past experiences with future anticipations. Some of them focused more on future anticipations than on painful experiences with their illness from the past, yet in most cases their stories develop in such a way that it seem to contribute to some form of assimilation and integration of suffering. Yet, the model on suffering of Eriksson needs some modification. The development of patients can be positive, without leading to a higher level of awareness, demonstrating greater spiritual strength. The stories showed a drive for finding a new balance, more harmony and an effort of relieving the pain of isolation and alienation caused by feelings of shame. We also recognized the need for restoring or maintaining dignity in the photo-stories. However, a direct confrontation with the sources of suffering as assumed by Eriksson in the struggle of *becoming* in suffering did not always seem feasible or even desirable for patients immersed in a severe, chronic mental illness. Eriksson's stages may reflect too high a

standard for the chronic patient population with which we worked. In our study suffering was often approached in a more roundabout way, as for instance in the case of Carl (described in chapter 3) who told he had taken up bicycling again and loved it. The hardships of the psychosis he had gone through was not explicitly mentioned, but it transpired through his feelings of relief that now he could be active again.

Whereas Eriksson emphasizes the need of reaching higher levels of spiritual strength through growing awareness and recognition of one's suffering, we found photo-stories that had all characteristics of façades. In our study we found façades in 15 out of 42 cases. Façades are stories that, according to Fredriksson & Lindström (2002) serve as make-believes that their owners use to hide from the true nature and magnitude of their suffering. Whereas Fredriksson & Eriksson (2001) seem to assume that façades are an obstacle for personal growth, our findings indicated that façades can function as an alternative to common acceptance strategies, such as facing one's losses and reconciliation. Basing ourselves on Charmaz (1991; 1999) we found that façades can create a distance between the person and the suffering that contributes to tackling suffering in an indirect way, not by confronting it but by circumventing it. Façades can fulfil useful, sometimes transitory, roles as was illustrated with three cases. The cases of Pieter, Judith and Tanja (chapter 3) showed us how their façades were functional in tackling their suffering and how it helped them to go on with their lives. Facades protect the storyteller from too direct a confrontation with their suffering. Façades are sometimes an intermediary step in a development in which one learns to face suffering more directly, but they can also offer an alternative to confrontation. We coined this "a being with suffering" and present this as a necessary revision of the theory on suffering.

Our differentiated approach of the complex process of suffering ties in with a narrative-based nursing that does not depart from fixed diagnostic criteria how to understand someone's reality and fault or right it, but tries to see how suffering works for *this* patient in *this* context. We take a phenomenological stand here that does not preclude that nurses at other moments do diagnose the state of a patient's health and well-being from a knowledge base and expertise in nursing. We think that in first hearing a patient's story nurses must bracket their knowledge of taxonomies of suffering to reach a fuller understanding of the phenomenon, and that the direction of this process of learning and understanding must be from *Verstehen* to *Erklären* (interpretation) and back again (hermeneutic circle). We criticize the concept of façade and the taxonomy of suffering for their neo-positivist overtones and their idealist expectations that run the risk of dictating us how to perceive the lived experiences of patients. The concept of façade in combination of the idea of climbing up in stages of suffering departs from two moral assumptions, namely:

1. hiding from truth prevents someone who suffers from personal growth;
2. truth can be determined as a monolithic entity that stands above the context it arises from and can be verified from common knowledge.

These moral assumptions may create unnecessary hindrances in creating a relational narrative (see chapter 4 and 6) as they invite caregivers to formulate a direction that stories should take (away from the façade) which patients may and most likely will not share. The idea of façades freezes as it were the conception of truth, whereas the therapeutic working of the photo-instrument is based on the assumption that narrative truth is versatile and will always be influenced by the specific conditions and context in which it is expressed. Central to a relational narrative is the dialogue between caregivers and patients. When a shared understanding of a patient's narrative has been established

then there may be room for more than one version of the direction a story may take. So, a taxonomy of suffering and different forms of acceptance (among which façades) may be useful at this stage, but only when nurses resist the temptation to use it for labelling instead of considering it as intermediary non-linear stages in a dynamic process of meaning making.

We think that the photo-instrument in this way can make a contribution to meta-cognitive therapies that aim at changing the way how patients think about how to cope with problems without tackling these problems themselves. The approach lies at the root of a training modulus called “Unravelling thoughts” that was developed in the Netherlands by Mark van der Gaag and Lucia Valmaggia (2005) for treatment of schizophrenia and that aims at looking closely in close collaboration with the patients how they conceive and interpret their perception of what goes on in their inner and outer world. Perception and conception are seen as two sides of the same medal determining behaviour in the interpersonal context. Photography is an intermediary between the outer and inner world. That makes it an apt medium for expressing and discussing how patients form cognitions of experiences in their life world.

Another strain of metacognitive therapy can be found in the Acceptance and Commitment Therapy (ACT): a behavioural therapy focused on acceptance with a strong emphasis on directing one’s behaviour in line with individual values (Hayes, 2004). ACT and the photo-instrument overlap where both depart from the notion of ‘a valued life’: patients can live a life based on values; they need not be overwhelmed by their problems, which can be bypassed or accepted for what they are when necessary. The focus of a valued life is important in trauma treatment. Photographs may help survivors of violence and abuse to verbalize difficult experiences and emotions and find

again a purpose of living, a personal meaning for life even where the present is painfully filled with despair (Sitvast, 2009).

The photo-instrument can also be seen as a form of experiential therapy, connecting it with hermeneutic therapies that put play and creative expression in the centre, as for instance is done in the experiential psychotherapy that was developed by Lubbers (2002). Actually, the experiential aspect of the photo-instrument has a potential to integrate it in a wide range of therapies or support programs that aim at re-socialisation. We will only mention one here: the intervention 'Seeking Safety', which was developed in Addiction Care. Seeking Safety is a present-focused therapy to help people attain safety from trauma/PTSD and substance abuse (www.seekingsafety.org). The attention given to the client's safety in domains of every day life, the integration of ideals and values into treatment and a focus on interpersonal relationships make Seeking Safety an apt therapy to host the photo-instrument as one of its tools.

3. What is the therapeutic role of the photo-instrument?

We found that the therapeutic effects of the photo-instrument are related to the patients' appropriation of their responsibilities. The instrument facilitates moral learning, by fostering a dialogue which enables people to experience themselves as narrators worthy to be seen and heard, without the need to be ashamed and withdraw from contact. Because people are invited to come forward and resist the clinical gaze of professionals, rehabilitation is promoted. While professionals must learn to suspend their diagnostic expertise in order to hear the stories of their patients, patients must learn that their stories can be told without being subjected to clinical appraisal or assessment. By meeting this

reciprocity of respect, a person will be reminded of who he really is or can become, even when this entails a far echo from a past that has receded almost into oblivion. This may kindle a spark of hope for recovery. We concluded that this is a first step out of invalidating contexts of self stigmatization and that it may precede further rehabilitation trajectories in which the emphasis is laid on improving skills and finding ways of making best use of residual abilities. The paradox is that nurses who sit still and receive the stories patients tell them, honouring them in this way, may engage the patients into a trajectory of change drawing on own resources of resilience. Then the relational narrative may become a journey of discovery during which the nurse is a travelling companion who sometimes can give you advice how to cope with the challenges on your way.

On a more concrete level, some of the photo stories give clear indications that patients perceived more control, self-efficacy, motivation to control and perceived competence. William (Chapter 4.), for instance, was motivated by his story to abstain from alcohol. Ellen, in chapter 2, perceived more control over her life when she saw herself not only as a victim of maltreatment by others. When this was not the case, for instance in the case of Judith (Chapter 3.) who did not experience more control, photo-stories still might contribute to a better understanding of nurses of the patient's needs and to more and better attuned access of the patient to sources and services. The photo-instrument did not contribute, at least not directly, to the participation of patients in decision-making settings. Yet, expressing one's wishes and goals may lead to advocacy. This became clear from a project (not included in our study) in which we used the photo-instrument to organise a photo exhibition about patients' preferences and wishes for new-to-build housing and present the outcome as a consumers' programme of demands.

We conclude that our findings confirm that moral learning facilitated by the photo-instrument is related to empowerment in three ways:

1. Psychologically the opportunity for voicing his story contributes to a patient's belief that his story matters and that his goals make a fair chance to be achieved.
2. Photographing what is important or dear to you heightens awareness of one's values and norms. The focus in the follow-up sessions on photographing a wish and what is necessary to realize it furthers a growing realistic insight in necessary skills, obstacles and sources of support.
3. Sharing one's own story with others in the context of photo group sessions and representing the result to family, caregivers and fellow patients on a photo-exhibition builds on people's identification and bonding with their social networks or place of residence. The recognition that one's story is credible restores the person in his or hers moral agency, thus making restitution of *face*.

The link with empowerment is corroborated by our findings in chapter 5, showing that patients progress in terms of an increasing openness and understanding of their feelings and situation. Openness and understanding also concern abilities to cope with feelings and situations. Patients show signs of hope and motivation to realize new future plans in line with their capacities. Contrary to the literature, we found no evidence of self-stigmatization and demoralization. This finding confirms that participating in photo groups can help patients to get along with their life and make it more bearable.

The photo-instrument can easily be combined with the implementation of the Strengths Model in recovery oriented rehabilitation programs. It shares with the

Strengths Model the focus on things that one holds valuable or are dear to someone and which are the basis for photographing a wish or goal to strive for in the near future. As a matter of fact the photo-instrument has already been integrated in the Strengths Model in a parallel instrument that we have called 'Recovery in Pictures'. In this intervention a photographer portrays a patient who steps besides daily routines and undertakes an action that furthers his recovery. One of the intervention's options is: walking on native soil. We literally travel back to places where memories of the past, possibly even of the period before one fell ill, can be remembered. It has become an exploration of patients' roots, but also of dreams and ambitions: who do you want to be as a person; how do you want others to see you and more basically how do you want to look like. These aspects were visualized by making photographs at crucial moments during the trajectory. One other possible combination of integrating the photo-instrument is using it as a tool in peer support groups. Experiential experts in mental health care who come together in self-directed group meetings may use the photo-instrument as a tool to find out what their sources of strengths are that have helped them in recovering from mental illness. Picturing one's own individual strengths is a very satisfactory thing to do and photographs facilitate sharing this with others. The iconic quality of many photographs used in this way makes it easier for experiential experts to capitalize on these strengths and use them for didactic purposes, for instance educating caregivers about the patient perspective.

4. What are the methodical implications for the application of the photo-instrument in the context of mental health care?

When patients are asked to make photographs, they are placed in another role. As photographer they are no longer the passive receivers of services of caregivers. They now come forward in an active role, expressing themselves with images and words and being admired for the courage to do so (McNamee & Gergen, 1992: 161). The camera that is handed over to them symbolizes an important change in direction: the patient is no longer the object that is being photographed, but becomes a subject taking his own photographs and telling (instead of being told) caregivers what the story is that the pictures show. For once not the caregiver, but the patient is the expert. Acting as a subject, someone becomes his own agent.

Hermeneutic photography contributes to promoting patients to become a subject again in still another way.

With the photo-instrument an appeal is made on patients to take up responsibility for the process of making meaning of difficult and often painful experiences in his life. Patients often find it hard to accept these experiences. Talking about them can be threatening, as it may revive the memory and feelings of chaos and turmoil that happened to them at a time of crisis and psychiatric decompensation. Making photographs is a way to channel diffuse and emotion-laden feelings and thought. The photographs function as intermediaries for meanings to become transparent. Photographs are carriers of meanings that invite reflection and exchange with others. In this way, a person can develop a grip on his situation where otherwise she may have the idea of being overwhelmed by it. As the patient may become an agent again in the interaction with others, this getting a grip on one's life stands for more agency in the intrapsychic interaction with one's own suffering. According to Ricoeur (1992), the experienced incapacity of acting is essential to suffering. This entails the feeling that things happen to you and that you cannot influence them. Restoring agency as is done in

the photo-instrument relieves suffering and establishes a basis for a new and more reciprocal relation with nurses.

Thus the photo-instrument can be considered a valuable expansion of the repertoire of interventions in health care. Another important contribution of hermeneutic photography to health care is the furthering of goal finding or goal readiness (discussed in chapter 4 and 5) and the anchoring of important personal issues in mental icons that lend patients a drive for action and that professionals can build on in their support of patient's recovery.

In the context of photo-groups, the act of expression encompasses the showing of photographs, the patients' reflecting on their meaning and sharing these pictured meanings with a public. This context facilitates a fusion of the sensual impressions, mimetic processes and social interaction. In this fusion, an image can obtain a therapeutic potential for committing the patient-photographer and his public to a shared understanding that can become the agenda for goal formulation and nursing support. The actions involved in the methodological procedure of the intervention have been shown to be congruent with its hermeneutic principles and with professional and patients' agendas of empowerment and recovery. Empowerment and recovery relate to domains of psychosocial rehabilitation in which psychiatric nurses have professional roles to fulfil. For this purpose the photo-instrument provides a powerful professional medium.

Lessons for theory and practice

1. What lessons can we draw from our study for further development of theory and praxis?

1.1. Implications for theory development

Focusing attention

Hermeneutic photography can help a person to find meaningful fragments in the diffuse totality of lived experiences and incorporate them into a process of truth-finding. This entails a lesson for philosophy, namely that truth-finding is engrafted on to contexts of every day practice and professional praxis, but also that it needs an act of exemplification to bring it to light, because otherwise it remains immersed in the flow of time and the unboundedness of space. Photography has a potential to stop time by freezing floating images in one picture within a spatial frame, thus accommodating reflection, association and negotiation over the layers of meaning hidden in the image. For this reason photography truly is a heuristic aid.

Inviting us to search for essential meanings

This is even working stronger through the illusion that a photograph represents life as it really is. This illusion paradoxically contributes to suspending the denotation of what is concretely pictured in the photograph in favour of the search for the essence of what life really is. The photograph and the invitation by nurses to tell about it provoke a prolonged oscillation between sense and image, reserved by Ricoeur (1977, p. 265) for poetry, but recognized by us in the way that patients build their photo-stories during sessions of the photo group.

Providing easy access to cultural mainstream

This mirror-play between sense and image reminds us of another interpretation of mimesis, namely the Platonic image of projection on the roof of the cave. Humans visualize, and human thinking is highly metaphoric (Lakoff & Johnson, 1980) and therefore related to imagery, more than to abstract rational concepts, although the visual and the verbal zones in the brain cortex are interconnected (Pavio, 1972). A metaphor is a way to understand an experience in terms of another experience (Lakoff & Johnson, 1980). For instance, the situation did not *feel* ((tactile sense) right. We did not trust (intuition) it. Another metaphor is the concept 'vision'. In our language the word vision is no longer used to denote physical observation by sight but to indicate that people feel a need for a mental image that integrates their understanding in a general impression. The metaphor *vision* is a transfer from the visual to the domain of thinking. It demonstrates how strongly thinking in imagery influences language itself, especially in conceptualizing. According to Lakoff and Johnson (1980) thinking is metaphoric to a large extent and most of the metaphors used in thinking are visual. In our study we found abundant examples of visual metaphors. Pieter for instance used the image of a tree that has become sick and mouldered to describe his own downfall because of schizophrenia (see chapter 3). Ellen used the imagery of light to tell she still hoped for a better life.

Today we live in an era where the visual is a dominant aspect of our culture.

Photography is an accessible medium with which most people are familiar. Its playful character appeals to many people. There is no specialist knowledge required to make photographs. As a matter of fact there are more photographs made with cell phones than ever before with photo cameras. Even chronic patients with severe mental health disorders can handle (or learn it) a digital camera.

We conclude that hermeneutic photography may pave the way for the development of a hermeneutic philosophy that incorporates visual texts.

1.2 Implications for health care praxis

Storytelling as a vehicle for recovery

Health care professionals, e.g. nurses, can learn from our findings that narrative is an important medium for patients to maintain themselves in life and keep up self-esteem. Narratives may be part of patients' strategies in facing losses, accept changed perspectives and find new hopes. Professional knowledge of narratives and underlying plots opens new possibilities for therapeutically influencing and supporting patients in their struggle for recovery. In fact, a narrative is a vehicle for patients to express their struggle of suffering and as we postulated that the patients' suffering is crucial in the patient-nurse communication, we consider nursing to be a narrative praxis that also needs a narrative theory to construct its operations and functionality (see also Sitvast, 2006, 2009).

Articulation of meaning by patients

Helping patients to find and express fragments of experience that stand out from the background is part of the art of nursing, representing a level of expert mastery of a trade that surpasses craftsmanship (Benner, 1984; Goudswaard, 1994). The fragments of lived experiences can be reworked into crystallizations of a process of making meaning from suffering and recovery. The photo-instrument may assist nurses in helping patients to exemplify particular moments and forge a 'real' experience (in the Gadamerian sense of

the word) from the flow of often intrusive and diffuse sensations that they incur from the impact of severe mental illness. This highlighting in images by which certain fragments of experience acquire special meaning (Radley, 1999; Benjamin, 1979) is an aesthetic aspect of meaning making.

Opening up to shared understanding

Nurses are sometimes too much focused on acting, and for that matter also on an acting that is based on their own professional estimation of patients' needs. Where wounds must be bandaged, acute crises must be warded off, etc., that may be good, but on other occasions it is more important to listen to patients in a responsive way without assessing how patient's needs fit in the professional jargon of nursing plans. Stimulated by the photo-instrument to bracket their own professional knowledge, nurses may more easily arrive at a shared understanding that can be taken as a point of departure for further actions to engage in (Gadow, 1999; Sakalys, 2000). Honouring a relational narrative (Abma, 2005) does not preclude that nurses may also voice views on the situation and state of health that conflict with the patient's view, but this should be part of a dialogue instead of coming from a position of 'we know what is best for you'.

Representation, performance and meaning construction are intrinsically linked

The praxis of the photo-instrument shows that a mimetic process of meaning making is intrinsically linked up with performance and cannot be seen apart from it. Actually it is a performative act that serves representation of the self. This performative act is set in a context of interaction between patients, caregivers, and wider circles of relatives and the public at large at the moment of exhibiting photo stories at an exposition. The representational agenda feeds back to the performance itself and to the process of

meaning making. The movement to and fro between interaction, representation and content mirrors the hermeneutic circle, describing how experiences from practice inform interpretation and the development of theory, which then again influences praxis. This intersubjectivity can be brought into play for therapeutic reasons more deliberately and with more awareness of its hermeneutic operation than is common in contemporary mental health care, constructing a therapeutic alliance with patients and finding a common ground for collaboration in treatment and support.

Future research

The findings of our study invite further investigations in more than one direction. To begin with there is the need for more research into the ways in which persons with severe mental problems give meaning to their suffering and how this impacts their daily functioning. Whereas stigmatization research focuses on the role that internal and external attribution plays in patients' narratives we think that, although this deserves special attention, it is too narrow to realize a broader understanding of the potential of these stories to reassert meaning to a disrupted life. We plead for a much broader study of patients' narratives. The epistemological role of concepts like façades can be further examined in relation to discourse analysis: how do concepts frame our thinking about recovery and empowerment? How do the stages of suffering formulated by Fredriksson and Eriksson (2001) and our suggestions for refining their model fit in here?

A second focus for future research may be the interrelated processes of recovery and empowerment. Based on our findings, the issue of moral learning should get a central place in this research. More research is needed into the possibilities for nurses to integrate moral learning and recovery into their praxis.

A third focus for future research is stigmatization. Although in our study we found no evidence of self-stigmatization and demoralization, more research with larger samples of patients is needed to explore whether other patients have a lowered self-image and if so, what distinguishes them from patients in our study, who seemed to show indifference to the impact of stigma. An interesting question related to stigmatization is whether a photo-exhibition could change stereotyped ideas of the general public about psychiatric patients

Next, the dialogical aspect of the photo-instrument might be further investigated, for instance by examining the response of close relatives, friends and neighbours to the patient's expression of a life with mental health problems. What did the photo-stories mean for the relation of patients with their relatives? We saw examples of improved relations between patients and their relatives (William for instance: see chapter 4) because of the potential of photographs to connect people and bridge adverse experiences of relatives with deviant 'psychiatric' behaviour, but we did not investigate this systematically.

Although the afore mentioned aspects need further exploration in qualitative studies they may also be translated in therapeutic outcomes that match validated instruments to measure them. Then a Randomised Controlled Trial would become possible to test effectiveness. In that case it would be wise to select one specific diagnosis cluster and focus on one target group of patients. When we assume that the photo-instrument contributes to a positive adaptation of patients to their proven vulnerability for a psychotic de-compensation, then the proposed study could be with patients who had a first psychosis which is in remission. The hypothesis might be that the photo-instrument realizes an increasing self-esteem and self-efficacy and a reduced need for care and

treatment. It can be argued that it does so by reducing a sense of shame and increasing a feeling of hope and trust in one's future. These effects are related to empowerment. We would focus on the following effects:

1. self-esteem
2. self-efficacy
3. need for care
4. shame
5. hope and trust/control over future

One of the validated outcome measures we could use is the Self-Esteem Rating Scale (Lecomte, Corbière & Laisné, 2006; Dutch translation Mark van der Gaag, 2004) developed for individuals with severe mental illness. Another outcome measure could be the Mental Health Confidence Scale (Carpinello, Knight, Markowitz & Pease, 2000; Dutch translation Castelein & Bruggeman, 2003) for measuring self-efficacy in individuals with severe mental illness. These outcomes measures can be researched in experimental groups and then be compared with control groups that may consist of guided peer support groups for psychosis (Castelein, 2009).

Another focus for future research would be the further exploration of the potential contribution of hermeneutic photography to the praxis of nurses and other healthcare workers. As a therapeutic intervention other applications of hermeneutic photography than the photo-instrument can be developed for use in health care settings (see e.g. Savolainen, 2008; Weiser, 1993). This would necessitate a feasibility study as also maybe the case with the photo-instrument itself.

In a feasibility study the focus would be on how nurses and other health workers consider the practical utility and value of working with the intervention.

Finally photography may be used as a research methodology offering chances to draw patients into the research as collaborators and co-researchers (Abma, Nierse & Widdershoven, 2009). This may give rise to new views on evaluation of health care programs, based on patients' experiences and needs, supplementing so-called routine-outcome monitoring in health care.

Strengths and weaknesses of the study

The photo-instrument was developed by us and further refined in the course of time. This can be seen as an advantage where it offered the opportunity for fine-tuning the instrument, enabling us to remove aspects that contradicted the therapeutic effects.

The ethnographic design of the study enabled us to combine participant observation with interviews and document analyses. The integration of findings from these data into the hermeneutic-phenomenological examination of texts and additional data rendered us a richer and more diverse insight of hermeneutic photography than would have been possible with text analyses only.

Mainly focusing on qualitative research, we were not able to measure therapeutic effects with validated outcomes. We consider this a necessary aim for a follow-up study. In a follow-up study some form of randomized controlled trial could also deal with the risk of unwantedly introducing a selection bias. We adopted a pragmatic sampling strategy based on restricted opportunities to set up photo groups and included as many participants as we could. The broad inclusion of patients however helped us to overcome a restricted focus on age groups and clusters of diagnosis and stimulated us to find what participants had in common in terms of recovery and meaning making.

Although we attributed the therapeutic effects to the operation of the photo-instrument, we are aware that some of the results may have been produced by a so called

Hawthorne-effect: the introduction of any new and evocative intervention is likely to effect a positive change, although the effect may last only for as long it is still experienced as new. Yet, it might also be assumed that the therapeutic effects of the intervention would have been greater if the intervention would have had more runs and would have been embedded more in treatment planning. As an isolated phenomenon, the intervention did not stimulate nurses and other professionals to integrate the challenges posed by photo-stories into treatment and nursing plans.

Future challenges

The challenge remains to make hermeneutic and narrative interventions like the photo-instrument more central to psychiatric nursing and rehabilitation. Therefore, a rethinking of the mission and principles of nursing is needed, and care ethical issues should get a more prominent place in the training and education of nurses and other caregivers. Other forms of therapeutic photography will have to be developed for new target groups of patients and consumers of care. This should not be restricted to mental health care, but also applied to somatic care. Initiatives in this direction have already been taken (see Report of the 2011 Turku Conference on Phototherapy). Moreover, outside direct patient care there are multiple possibilities to apply hermeneutic photography for other reasons than its therapeutic effects. It can be applied to organizational development. The photo matrix method for instance is used to find hidden truths in organisations (Hupkes, Nijhuis & Kuiper, 2011).

Epilogue

Jan Arends wrote poems as thin trees, thus strongly communicating his pains on paper. Yet, we know that he often felt that he was not able to make real contact (Keunings,

2002). This pain is shared by many others who experience the same loneliness in their suffering from severe mental illness. Their pain becomes ours as we realize how we as caregivers apparently have failed them, because we did not hear their stories or, where we did hear them, could not communicate that we heard them and that we acknowledge them for the vulnerability and their strengths in the face of life's inequities that connects us on a very deep level of shared humanness. We believe that nurses with the photo-instrument can make a change and reach out to suffering patients that come towards them for help. Jan Arends' poem expresses his loneliness without offering a point of contact for health care professionals or for himself to grow and develop a story that is more open to change. In the photo-instrument the dialogue that is so strikingly absent in Arend's poem is somehow realized. Thus, the photo-instrument can serve not only as a vehicle for expressing suffering, but also as a relational instrument connecting people and helping them to gain a richer life.

Summary

The general aim of this thesis was to examine how nurses can use photography to assist psychiatric patients in making meaning of experiences of illness and to help them in the process of recovery. The study is based on a hermeneutic-phenomenological perspective, focusing on processes of experiencing and meaning making in the life world. Existential issues, e.g. the way how people give meaning to their suffering, play an important role in this process of being-in-the world. From a hermeneutical-phenomenological perspective, caring can be seen as the core mission of nursing, tying in with a definition of health and health promotion that is broader than the absence of physical defects and functional impairments and encompassing quality of life and the possibilities for directing one's life, even when one feels impeded by the impact of sickness. Caring can be seen as rooted in the nurses' response to the suffering of patients, which we conceptualized as a lack of agency (Ricoeur, 1992). 'Agency' concerns the extent of direction people feel in exercising influence on domains of their lives that matter to them. Whereas patients' suffering compromises their agency to direct their own lives (being impeded by the impact of illness), nurses' caring focuses on giving attention to the patient's needs, e.g. safety, comfort, relieve of pain and stress, etc. By responding to their needs, nurses empower patients and strengthen their agency. Processes of meaning making and expression of suffering in narrative play a crucial role. Since narratives are based on a shared understanding between patients and nurses and other caregivers, narratives are relational. Relational narratives are developed through dialogical interaction. We connected this conception of a relational narrative with the agenda of recovery and empowerment, which stands for the struggle of patients in mental health care to live a life beyond illness and regain more agency and more

direction in life in order to realize a better quality of life. Basing ourselves on Gadamerian hermeneutics we postulated that the (facilitation of) expression of this struggle plays an important role in the process of meaning making which underlies recovery.

Departing from these notions we examined hermeneutic photography, assisting people in constructing meaning from experiences in their life world. More concretely we examined our application of hermeneutic photography: the photo-instrument. We did so from two perspectives, that of meaning making and that of the therapeutic potential in the context of nursing. In chapter 2 we studied how the hermeneutic philosophy of Ricoeur could provide us with a theoretical framework to understand processes of meaning making. In chapter 3 the focus is still on processes of meaning making, but now more from a phenomenological point of view, i.e. departing from the existential problem of suffering we found in empirical data. In chapter 4 and 5 we shifted the focus to the therapeutic significance of the intervention. In chapter 6 we described the methodical steps (actions) of hermeneutic photography as a nursing intervention and discussed what it might contribute to professional agendas of recovery-oriented rehabilitation.

The photo instrument as nursing intervention

The specific application of hermeneutic photography that we used was the photo-instrument. The photo-instrument has been developed by the author in an action research during which the intervention has been adapted, complemented and refined over a period of two years (2000-2002) and repeatedly tested with new groups of patients in mental health care (Bouhuis et al, 2003). The result was a protocolled intervention that nurses and other health professionals can use to direct group sessions with patients who

are no longer in a hectic period of psychiatric crisis behind them and are working on further recovery.

The intervention contains individual assignments to make photographs. The results are discussed in group meetings. At the start the participating patients receive a disposable camera. The first assignment instructs participants to make photographs of what they value as important in their lives here and now. These photographs are then used for further exploration of the photographer's subjective experiences. In a number of group sessions facilitated by two health workers (e.g. a nurse and an occupational therapist) participants select photographs and stories that belonged to them for an exhibition aiming at a wider public. Every participant presents his or her own photo-story. After the exhibition the cycle is repeated with a new assignment. The assignment now challenges participants to imagine who they want to be or what they would want to achieve in one or two years from now and what obstacles and chances they will meet on the route. This round of group sessions also ends with an exhibition of photographs and text that tells the story of every individual participant (see the appendix for the manual with detailed steps and instructions).

Three elements constitute the intervention's therapeutic potential, namely:

1. the process of individual reflection on the meaning of photographs made by every patient as an outcome of the assignment to make photographs of one's life world.
2. the process of expressing these meanings and claiming owner-ship of them as representations of one's identity
3. the process of sharing the photographs and communication to relevant others. This creates a visibility that gives participants the feeling of being acknowledged for who they are as a person, not limited to being a psychiatric patient.

Dialogue plays an important role in the intervention's procedures. This explains why the photo exhibition at the end feels like crowning the whole enterprise. The photo-stories that have cost a lot of energy, emotion, pondering, wishing and also sometimes regretting of impossibilities that beset its planning, now come into the open and are showed to the outside world. Their reception by others can be benevolent or hostile. The nurse or other health professional who acts as a group facilitator has an important role in directing this process towards a safe haven and to make possible that participants experience positive reinforcement for their daring and brave openness.

Meaning making in chronic psychiatry

In our research we used two perspectives. One is the perspective of meaning making and the other is the therapeutic potential in the context of nursing. We will now summarize our findings and start with 'meaning making'.

In chapter 2 we examined whether the writings of the French philosopher Ricoeur (1913-2005) offers a theoretical framework from which we can derive concepts that help us understand the process of meaning giving in the context of the lives of persons with mental health problems. We made use of an exemplary case to illustrate how participants in our research had set about the process of meaning making. We found that the photo group provided a context in which one participant called Ellen started to reflect on her experiences and in the end formulated a new perspective and integrated this in her life story. Her suffering became transformed when she recognized that she was not just a victim of the situation, but that she had created obstacles that she could overcome. The process of reconstructing her experiences in order to find new meanings was found to match Ricoeur's interpretation of mimesis. Mimesis is a creative process of

interpreting a narrative in such a way that the listener or reader of the text integrates its meaning in his own frame of reference and appropriates it as a story that he recognizes as relevant for himself. Ricoeur's concept of mimesis made it possible to comprehend how Ellen was so entrapped in her direct first-hand experiences that she first needed some distance between herself and the lived experiences. Making photographs seemed to provide this distance. This is the distanciation described by Ricoeur as a step within the process of mimesis. The widening of contexts was the next step: it opened the way for Ellen to another interpretation of reality, for instance that her suffering might also be attributed to intrapersonal factors. Ricoeur has described how imagery and metaphors go hand in hand in giving new insights. We observed this in Ellen where she used the metaphor of lanes leading her out of darkness to the light, beautifully pictured with photographs of lanes in the wood. In line with Ricoeur's interpretation of mimesis, this helped Ellen to reformulate her lived experience and plot a new story that enabled her to make her own choices in life.

In chapter 3 we focussed on the aspect of suffering. Patients suffer from the impact of illness on their daily lives. We became aware that suffering of patients can mute their voice. Patients sometimes shrink from expressing their suffering as people around them not always bear to listen and are frightened away. This may evoke feelings of shame in the patient. We saw examples of this in photographs that participants did not want to comment on. To further explain this, we compared our findings with studies about suffering by Fredriksson and Eriksson (2001). We used their model to identify transitional stages in how patients struggle with suffering in an effort to find meaning. The essence of the struggle of suffering is the conflict between shame and dignity. It is a struggle to make yourself heard. Only when someone succeeds at having his true self

confirmed by others then shame can be overcome. Although we could confirm this development for Ellen and for some of the other participants in our study, we found indications that the model does not exhaust all possible other variants of meaning giving to suffering. Façades were identified in the participants' photo-stories, shedding another light on the therapeutic role of the photo-instrument. Three cases were analysed in more detail. In the case of Pieter the façade was a polished story with images of nature, lacking depth and with a make-believe quality to it. This façade protected him from premature self-disclosure. In the case of Judith the façade was a theatrical staging of her helplessness, interpreted by us as serving to protect her from feelings of failing her own expectations. In the case of Tanja the façade was a clinging to her wish of making professional photographs in the future that stood in no relation with her unstable situation at that moment. We interpreted this as a withdrawal from her suffering to find a temporary respite and at the same time we recognized that the image functioned as a beacon for her to focus on that helped her to keep intact the integrity of her self. This seems to indicate that patients do not always need to confront their suffering, as is assumed by Fredriksson and Eriksson, but that circumventing suffering may be helpful, though sometimes only temporary, to integrate it in their lives.

Another notable finding was that there is an important difference between an *established* identity and an *accepted* identity as a 'mental patient'. In stigmatization studies this distinction reflects the degree to which patients have internalized lowered self-esteem and expectancies of life. The three cases we analysed show that all three clients were fully aware of their being a mental patient, but also that their stories reflected this in diverse ways. They did not really accept the identity endowed to them by others. This confirms Van 't Veer's study (2006) on stigmatization processes

where he found that most people had established identities as a patient, but only a small percentage had also accepted it in terms of attributing stigma internally.

Therapeutic significance of the photo-instrument

We will now summarize findings from the second perspective of our study: the therapeutic potential of the photo-instrument.

In chapter 4 we returned to communicative aspects of performance and representation. We focused on *how* participants used photo-stories to represent themselves and show to others who they are and what they think is important in their lives. By showing their photographs to others in a public photo exhibition, participants indicated how they wanted to be seen by others. We related our findings from cases in our study to Goffman's concept of impression management and concluded that the representation with photo-stories goes beyond smoothly interacting and making a good impression, because it invites participants to assume responsibilities and take up new roles in their lives. We turned to hermeneutic philosophers like Ricoeur, Levinas and MacIntyre for reasserting the importance of ethics in sustaining psychological continuity and experiencing moral identity in one's life. We adopted the concepts of *face* and *voice* from these hermeneutic philosophers and sociolinguistics (e.g. Goffman, 1959) in order to reach a better understanding of the dynamics of interaction within cases from our study. We postulated that patients suffering from severe mental problems make a moral appeal on caregivers to respond to their photo stories in a way that recognizes their authentic selfhood behind their suffering. As Hinshaw (2007) and Corrigan & Watson (2002) and other authors on stigmatization argue, as a consequence of persistent effects of psychiatric symptoms and self-stigmatization, persons with severe mental problems

who have been treated for a long time often have lost their credibility in their own eyes and those of others over the years. Our findings, illustrated with 2 cases (William and Benny), confirm that persons with a psychiatric disability in a photo group may wrestle to find new credible selves and that moral learning can be part of an interaction with the social environment. We described the potential for a care ethical approach that wants to restore face to a person and hear the voice that may otherwise be muted. We connected this with the nursing agenda of rehabilitation and facilitating recovery by demonstrating how nurses and other caregivers can use the social context of the photo-instrument to foster moral learning. Moral learning involves taking up responsibilities by patients, for instance the role of being a father by William, and Benny's insight that success in life means taking first steps, developing oneself and being responsible for one's life.

In chapter 5 we focussed on the patients' perception of the impact of mental illness on their daily functioning. From studies on stigmatization (Corrigan & Watson, 2002; Hinshaw, 2007; Link et al., 1989; Wright, Gronfein & Owens, 2000) we learned that there are several possible responses to stigmatization:

1. self-stigmatization that results in a decreasing self-esteem,
2. righteous anger that fuels becoming active in advocacy and empowerment efforts
3. indifference to the impact of stigma altogether

At the same time we concluded that much is still unknown about how persons experience a life with mental illness. We adopted a mixed methods design aimed at finding out how the photo-instrument influenced the perception of patients of the impact of sickness on their daily lives. We measured changes in perception with the Sickness Impact Profile (SIP), a questionnaire with a pre-post test design. The findings indicate

an absence of significant changes in the overall SIP scores except in the domain of mobility. This domain entails daily tasks like shopping, house cleaning, taking care of personal business affairs and social calls on relatives and friends. Other domains of the SIP concern the individual's control over somatic and motor functions, psychological and (social) behavioral functions and the regulation of emotions. Some of these domains reflect somatic issues that were hardly relevant for the participants in our study. It may explain why no significant outcomes were measured on these domains of the SIP.

Differentiating between inpatients and outpatients we found a significant reduction in the outpatient group for the domain of social behavior. This domain relates to patients' perception of the influence of illness on social functioning in relation to other persons (spouse, children and "other people" in general). Sexual activity, visiting friends and activities in groups of people are items in this category, as well as doing chores in and around the house and recreational activities.

The outcomes from the SIP were used to differentiate between respondents who perceived less impact of sickness on their daily lives after following a photo group from those who did not or remained the same. The subgroup of outpatients showed a reduction in perception of the impact of illness. The absence of any statistically significant reduction in the group of inpatients might be the result of the domains of mobility and social behaviour reflecting a domestic situation that fits much more the situation of outpatients than that of inpatients, living in a hospital setting. Findings from in-depth interviews among inpatients (long stay) and mentor nurses show that patients, irrespective of changes in their perception of the impact of illness on their lives, have a pretty realistic view on their limitations and how these affect their daily functioning.

We found that this does not lead to adjusting the self-image in a negative downward spiral to a numb identity as chronic patient. Patients still long for a 'normal' life in which they can make independent choices, run their own household, have meaningful activities at their hands, see friends and family and maybe go on a holiday every now and then. In this respect patients fit the category that Corrigan and Watson (2002) had in mind when they distinguished the third group of patients showing indifference to the impact of stigma.

In therapeutic terms the findings in chapter 5 show that through the opportunity of telling their story some patients progress in terms of an increasing openness and understanding of their feelings and situation. Patients showed signs of hope and motivation to realize new future plans in line with their capacities. The communication with the nurses improved and more openness triggered a better tuning of care to patients' needs.

Methodical actions to foster meaning making in psychiatric practice

In the last study, we investigated how the photo-instrument can be used by nurses and other health care workers as a professional intervention.

In chapter 6 we analysed the intervention from a methodical point of view. A comparison with existing literature showed that there are only few studies that report on the use of hermeneutic photography in clinical settings, let alone in mental health care. Most examples of hermeneutic photography are found in social and health research without any therapeutic aims. Hermeneutic photography is rooted in hermeneutic philosophy. This comes to the fore in the actions health care professionals, e.g. nurses,

take in executing the intervention. Methodically the intervention works in steps or actions, making operational the two central concepts, namely *mimesis* and *performance*. These steps combine hermeneutic actions, group dynamic interventions and actions that promote expression.

An example of this is the continuous process of reflection and dialogue between group facilitators and participants during all sessions. We found that the setting of a photo group feels safe enough for patients to engage in a dialogue with the group facilitators and fellow group members. Thus the photo-instrument facilitates storytelling. Another example is how group facilitators stimulate participants to listen to stories of other participants and to respond to them in a positive way. The photo-exhibition at the end of the trajectory connects group members and facilitators and ties them to a shared goal. These actions and other trigger a form of collaboration between patients and professionals that we consider as one of the strengths of the photo-instrument, touching on the intention of many health care professions to build therapeutic alliances. By therapeutic alliances we mean the kind of contact between patients and caregivers that aims at helping patients to express their needs and worries, entertain hope again and find a goal in life. This is closely interwoven with the professional agenda of empowerment, experience-focussed care and rehabilitation/recovery. The photo-instrument can be considered as a toolbox serving this agenda.

When we pull together everything that has been argued in this thesis, then we reach the conclusion that the photo-instrument is an apt intervention for nursing professionals to facilitate a process of meaning making in patients who struggle with experiences with illness and suffering. It does not focus on suffering alone, but encompasses the

possibilities for making one's own choices and taking up new roles and responsibilities. These latter issues we have identified as a form of moral learning. The collaboration between patients and nurses to this aim can be seen as one of the strengths of the intervention. The photo-instrument allows patients to direct the interaction more on their own terms. Making photographs they are no longer the passive receivers of services of caregivers. Expressing themselves with images and words they play an active role in the communication with caregivers. Another asset is that the intervention facilitates a patient to take a meta-position in relation to his suffering, thus creating room for reflection. The commitment of the intervention to real life experiences and its focus on values, wishes and ambitions are factors that lend this process of reflection a positive but realistic character.

These qualities represent a therapeutic potential for integrating or combining the photo-instrument with other therapeutic approaches and programs. The Strengths Model approach in recovery oriented rehabilitation comes to mind first, but we can also think of meta cognitive therapies and training in treatment of schizophrenia, as well as trauma treatment and resocialisation programs in which an experiential focus on every day life and interpersonal relationships is combined with attention to ideals and values. How the photo-instrument connects with this wider area of therapy has been described in the Discussion paragraph.

For more information on how to do the photo-instrument yourself, please consult the website:

www.fototherapie.startje.com (in Dutch)
or contact me:
j.sitvast@ggnet.nl

Samenvatting

Het algemene doel van dit proefschrift was te onderzoeken hoe verpleegkundigen fotografie kunnen gebruiken om psychiatrische patiënten te helpen betekenis te geven aan ervaringen van ziekte en hen zo te helpen in hun proces van herstel. De studie is gebaseerd op een hermeneutisch-fenomenologisch perspectief en focust op processen van beleving en betekenisgeving in de leefwereld. Existentiële zaken, zoals de manier waarop mensen betekenis geven aan hun lijden, spelen een belangrijke rol in het proces van-in-de-wereld-staan.

Vanuit een hermeneutisch-fenomenologisch perspectief kan het zorgen beschouwd worden als de kernmissie van verplegen. Zorgen is verbonden met een definitie van gezondheid en gezondheidsbevordering die breder is dan de afwezigheid van lichamelijke defecten en functionele beperkingen. Gezondheid(sbevordering) omvat kwaliteit van leven en de mogelijkheden om je leven te sturen, zelfs als je daarin belemmerd wordt door de gevolgen van ziekte. Het geven van zorg is geworteld in het antwoord van de verpleegkundige op het lijden van patiënten, dat we met Ricoeur (1992) begrepen als een tekort aan zeggenschap ('agency'), hier bedoeld als dat mensen door hun ziekte onvoldoende sturing kunnen geven aan en invloed uitoefenen op voor hen belangrijke zaken in het leven. De zorg van verpleegkundigen focust op behoeften van de patiënt, bijv. de behoefte aan veiligheid, comfort, verlichting van pijn en stress, enz. Door aandacht voor deze behoeften versterken verpleegkundigen het zelfvertrouwen van patiënten en vergroten ze de zeggenschap die patiënten ervaren om hun eigen leven te sturen. Het geven van betekenis hieraan en de uiting of expressie gebeurt vaak door te vertellen wat men ervaart. Verhalen spelen daarom een cruciale rol.

Als verhalen gebaseerd zijn op een elkaar begrijpen van patiënten en verpleegkundigen, dan worden het gedeelde verhalen ('relational narratives'). Gedeelde verhalen ontwikkelen zich in een dialoog met elkaar. We hebben het concept van gedeelde verhalen verbonden met de agenda van herstel en empowerment, dus met de worsteling van patiënten in de GGZ om een leven te leiden dat boven de ziekte uitgetild kan worden en waarin men meer zeggenschap en sturingsmogelijkheden heeft om een bevredigend kwaliteit van het dagelijks bestaan te realiseren. Ons baserend op de hermeneutiek van Gadamer gaan wij er vanuit dat deze worsteling om het bestaan en de ondersteuning daarbij een belangrijke rol spelen in het proces van betekenisgeving bij herstel.

Vanuit dit denkkader hebben wij onderzocht hoe hermeneutische fotografie mensen ondersteunt in het geven van betekenis aan ervaringen in hun leefwereld. Meer concreet onderzochten we een bepaalde toepassing van hermeneutische fotografie: het door ons ontwikkelde foto-instrument. We lieten ons daarbij leiden door twee perspectieven: dat van betekenisgeving en van het therapeutische potentieel in de context van verplegen. In hoofdstuk 2 hebben we gekeken hoe de hermeneutische filosofie van Ricoeur ons een theoretisch raamwerk kon bieden voor het begrijpen van processen van betekenisgeving. In hoofdstuk 3 ligt de focus nog steeds op het proces van betekenisgeving, maar nu meer vanuit een fenomenologisch standpunt, dat is: het vertrekpunt ligt nu bij het existentiële probleem van het lijden zoals we dat in de empirische data aantreffen. In hoofdstuk 4 en 5 verschuiven we de focus naar de therapeutische betekenis van de interventie.

. In hoofdstuk 6 hebben we de methodische stappen (acties) beschreven van hermeneutische fotografie als een verpleegkundige interventie en hebben we ons

afgevraagd wat de interventie zou kunnen bijdragen aan de professionele agenda's van empowerment en herstelgeoriënteerde rehabilitatie.

Het foto-instrument als verpleegkundige interventie

De specifieke toepassing van hermeneutische fotografie die we hebben gebruikt heet het foto-instrument. De interventie is door de auteur ontwikkeld in een actieonderzoek van 2 jaar (2000-2002), tijdens welke ze aangepast, aangevuld en verder verfijnd is. Ze is herhaaldelijk getest met steeds nieuwe groepen patiënten in de GGZ (Bouhuis et al, 2003). Het resultaat was een geprotocolleerde interventie. Verpleegkundigen en andere gezondheidszorg professionals kunnen haar gebruiken voor groepsbijeenkomsten met patiënten die uit de fase van een psychiatrische crisis zijn en bezig zijn met hun herstel.

De interventie vertrekt vanuit de individuele opdracht aan deelnemers om foto's te maken. De resultaten worden besproken in groepsbijeenkomsten. Tijdens de eerste bijeenkomst krijgen deelnemers een wegwerpcamera. De opdracht instrueert deelnemers om foto's te maken van wat zij in het leven hier-en-nu belangrijk en waardevol vinden. Deze foto's worden vervolgens gebruikt voor een verkenning van de subjectieve belevingen van de fotograaf. In een aantal groepsbijeenkomsten, die begeleid worden door twee hulpverleners (bijv. een verpleegkundige samen met een activiteitentherapeut) selecteren de deelnemers een aantal foto's waarmee zij een verhaal vertellen en bestemmen die voor een fototentoonstelling waarvoor ook andere mensen dan de deelnemers worden uitgenodigd. Elke deelnemer presenteert op de tentoonstelling zijn eigen fotoverhaal. Na de tentoonstelling volgt een nieuwe ronde met een nieuwe opdracht. De opdracht is nu aan deelnemers om zich voor te stellen wie ze willen zijn of wat ze zouden willen bereiken over een of twee jaar. Ook welke belemmeringen en kansen ze zullen tegenkomen op hun pad. Deze ronde van bijeenkomsten wordt ook

weer afgesloten met een tentoonstelling waarop deelnemers hun individuele verhaal vertellen (zie de bijlage met de handleiding voor een gedetailleerde beschrijving van stappen en instructies).

Het therapeutische potentieel van het foto-instrument wordt bepaald door 3 elementen, namelijk:

1. het proces van individuele reflectie op de betekenis van de foto's die de patiënt heeft gemaakt van zijn leefwereld
2. het proces van expressie: het tot uitdrukking brengen van betekenissen en het kunnen erkennen dat ze staan voor wie je bent (representatie van de identiteit)
3. het proces van het delen van de foto's met en het communiceren naar belangrijke Anderen. De zichtbaarheid die met foto's ontstaat, geeft deelnemers het gevoel van erkend te worden in wie ze zijn als persoon zonder dat dit versmald wordt tot het psychiatrisch patiënt-zijn.

In de procedures van de interventie speelt de dialoog een belangrijke rol. Dat verklaart waarom de fototentoonstelling aan het eind wordt ervaren als een apotheose, een bekroning van de hele onderneming. Het tot stand komen van de fotoverhalen heeft de deelnemers veel energie gekost en is soms een emotioneel proces. Het nadenken gaat gepaard met verlangens en wensen en soms met spijtgevoelens over onmogelijk geworden kansen in het leven. Met de tentoonstelling komt het naar buiten en wordt getoond aan de buitenwereld. De ontvangst door anderen kan welwillend zijn of vijandig. De verpleegkundige of andere professional die de fotogroep begeleidt, heeft een belangrijke taak in het sturen van dit proces naar een veilige haven en het mogelijk

te maken dat deelnemers positieve bekrachtiging kunnen ervaren voor hun gedurfde en moedige openheid.

Betekenisgeving in de chronische psychiatrie

In ons onderzoek gebruikten we twee perspectieven. De een is betekenisgeving en de ander is het therapeutisch potentieel in het kader van verplegen. We zullen nu onze bevindingen samenvatten en beginnen met betekenisgeving.

In hoofdstuk 2 onderzochten we of met het werk van de Franse filosoof Ricoeur(1913-2005) een denkkader hebben waaraan we concepten kunnen ontlenuen die ons helpen het proces van betekenisgeving beter te begrijpen bij mensen met psychische problemen. We maakten gebruik van een exemplarische casus om te laten zien hoe deelnemers aan ons onderzoek het proces van betekenisgeving ter hand hadden genomen. We zagen dat de fotogroep een context bood voor deelnemer Ellen om te reflecteren op haar ervaringen en uiteindelijk een nieuw perspectief te formuleren en dit te integreren in haar levensverhaal. Haar lijden werd getransformeerd toen ze inzag dat ze niet zomaar een slachtoffer was van omstandigheden, maar dat ze zelf obstakels had gecreëerd die ze moest overwinnen. Het reconstructueren van haar ervaringen om uiteindelijk nieuwe betekenissen te vinden bleek goed verklaarbaar met Ricoeur's interpretatie van *mimesis*. Mimesis is een creatief proces van hoe een verhaal zo kan worden geïnterpreteerd dat de luisteraar of lezer de betekenis ervan integreert in zijn eigen wereldbeeld en het verhaal zich 'toe-eigent' als slaand op zichzelf. Ricoeur's uitleg van het begrip mimesis opende ons de ogen voor het feit dat Ellen zo geobsedeerd was door haar directe ervaringen dat ze eerst afstand nodig had tussen zichzelf en de herinnering aan wat ze beleefd had. Het maken van foto's leek voor afstand te zorgen. Dit noemt Ricoeur 'distanciation', het

zetten op afstand van de directe ervaring. Het is een eerste stap in het proces van mimesis. Een volgende stap is de verbreding van de horizon. Dat opende voor Ellen de toegang tot een andere interpretatie van de werkelijkheid, bijv. dat haar lijden misschien wel toegeschreven kon worden aan intrapersonlijke factoren. Ricoeur heeft beschreven hoe beeldspraak en metaforen samen gaan bij het ontwikkelen van nieuwe inzichten. We herkenden dit bij Ellen toen ze de metafoor gebruikte van paden die haar uit het donker naar het licht leidden, prachtig verbeeld met foto's van bospaden. In overeenstemming met Ricoeur's interpretatie van mimesis, hielpen de beelden een metafoor te vinden om haar ervaringen te herformuleren en een nieuw verhaal te bedenken met een plot die haar in staat stelde zelf keuzes te maken in het leven.

In hoofdstuk 3 richtten we ons op het aspect van het lijden. Patiënten lijden door de impact die ziekte heeft op hun dagelijks leven. We werden er ons van bewust dat het lijden patiënten kan doen verstommen. Soms zien patiënten er vanaf om zich uit te laten over hun lijden omdat mensen in hun omgeving er niet tegen kunnen om er naar te luisteren en er door afgeschrikt worden. Hierdoor kunnen bij de patiënt gevoelens van schaamte ontstaan. We zagen hiervan voorbeelden in foto's waarover de makers, deelnemers aan fotogroepen, niets wilden zeggen. Door onze bevindingen te vergelijken met wat Fredriksson en Eriksson (2001) daarover meldden in hun studies over het lijden, kregen we hiervan een beter beeld. We gebruikten hun model om overgangsfasen te herkennen in de worsteling van patiënten om betekenis te vinden. De essentie van de worsteling van het lijden is het conflict tussen schaamte en waardigheid. Het is een strijd om gehoord te worden. Pas wanneer iemand erin slaagt om zijn ware ik bevestigd te krijgen door anderen kan schaamte worden overwonnen. Ook al konden we dit terugvinden in de ontwikkeling die Ellen doormaakte en ook bij sommige andere

deelnemers in ons onderzoek, moesten we toch constateren dat het model niet alle mogelijke varianten van betekenisgeving aan individueel lijden weergaf. We herkenden façades in de fotoverhalen die een ander licht wierpen op de therapeutische rol van het foto-instrument. Drie cases werden door ons geanalyseerd. In het geval van Pieter bestond de façade uit natuurfoto's die diepte misten en een verhaal dat mooier was dan de rauwe werkelijkheid eronder. De façade beschermde hem echter voor een te vroege zelfonthulling. In het geval van Judith bestond de façade uit een theatrale opvoering van haar hulpeloosheid. Door ons geïnterpreteerd als haar behoedend voor de teleurstelling van niet uitgekomen verwachtingen van eigen kunnen. In het geval van Tanja was de façade een vastklampen aan haar wens om in de toekomst professionele foto's te maken. Een verwachting die in schril contrast stond met haar onstabiele situatie op dat moment. Wij interpreteerden dit als een terugtrekken uit haar lijden om tijdelijk rust te vinden, maar we zagen tegelijkertijd dat het beeld dat ze van zichzelf had functioneerde als een baken waarop ze zich kon focussen en dat haar hielp om de integriteit van haar zelfbeeld te bewaren. Het bleek dat patiënten niet altijd hun lijden onder ogen hoeven te zien, zoals wel verondersteld in het model van Fredriksson en Eriksson, maar ook er om heen kunnen gaan en dat dit hen, al dan niet tijdelijk, hielp in hun verwerking.

Een andere noemenswaardige bevinding was dat er een belangrijk verschil is tussen een *toegekende*, 'verworven' identiteit en een *geaccepteerde* identiteit als psychiatrisch patiënt. In stigmatiseringstudies weerspiegelt dit onderscheid de mate waarin patiënten een lager zelfbeeld en verminderde verwachtingen van wat het leven te beiden heeft hebben geïnternaliseerd. De drie cases die we geanalyseerd hebben laten zien dat alle drie cliënten zich volledig bewust waren van het feit dat ze een psychiatrische patiënt waren, maar ook dat hun verhalen dat op verschillende manieren weergaven. Zij

accepteerden niet echt de identiteit die anderen aan hen koppelden. Dit bevestigt Van 't Veer's studie (2006) naar processen van stigmatisering waarin hij vond dat de meeste mensen een identiteit hadden toegekend gekregen/verworven als patiënt, maar slechts een klein percentage dit ook had geaccepteerd door het stigma toe te schrijven aan eigen kenmerken (interne attributie).

Het therapeutische belang van het foto-instrument

We zullen nu een samenvatting geven van onze bevindingen vanuit het tweede perspectief van onze studie: het therapeutische potentieel van het foto-instrument.

In hoofdstuk 4 keerden we terug naar communicatieve aspecten van uitvoering ('performance') en representatie. We richtten ons op *hoe* deelnemers fotoverhalen gebruikten om een representatie van zichzelf neer te zetten en aan anderen te laten zien wie ze zijn en wat ze in hun leven belangrijk vinden. Door hun foto's te tonen op een openbare fototentoonstelling gaven de deelnemers aan hoe ze door anderen gezien wilden worden. We brachten onze bevindingen in verband met Goffman's concept van 'impression management' en concludeerden dat de representatie met fotoverhalen verder gaat dan een geoliede interactie die draait om het achterlaten van goede indrukken. De fotoverhalen bleken de deelnemers uit te nodigen tot het oppakken van verantwoordelijkheden en nieuwe rollen in het leven. Met hulp van hermeneutische filosofen als Ricoeur, Levinas en MacIntyre konden we het belang van de ethische component aantonen voor het bewaren van een psychologische continuïteit en het kunnen ervaren van een morele identiteit in het leven. We hebben van deze hermeneutische filosofen en sociolinguïsten (bijv. Goffman, 1959) de begrippen *face* en *voice* overgenomen om beter te begrijpen welke dynamiek er is in de interactie tussen

deelnemers aan onze studie en hun omgeving. We hebben verondersteld dat de patiënten die aan ernstige psychische stoornissen lijden een moreel appel doen op hulpverleners om op een zodanige manier op hun fotoverhalen te reageren dat ze erkenning krijgen voor hun authentieke zelf dat verborgen ligt onder hun lijden. Hinshaw (2007) en Corrigan & Watson (2002) en andere auteurs die geschreven hebben over stigmatisering beweren dat ten gevolge van aanhoudende effecten van psychiatrische symptomen en zelfstigmatisering, mensen met ernstige psychische problemen waarvoor ze al een lange tijd behandeld worden, in de loop van de tijd hun geloofwaardigheid dreigen te verliezen, niet alleen in de ogen van anderen maar ook van zichzelf. De bevindingen van onze studie, geïllustreerd aan de hand van 2 cases (William en Benny) bevestigen dat mensen met een psychiatrische handicap soms worstelen om een nieuw, geloofwaardig beeld van zichzelf te vinden. De morele aspecten hiervan maken dat we dit benoemd hebben als een moreel leren dat deel uit kan uitmaken van de interactie met de sociale omgeving. Op grond hiervan hebben we de mogelijkheden beschreven van een zorghistische benadering die een mens weer aanzien (face) wil geven en een stem (voice) die anders mogelijk verstomd blijft. We hebben dit verbonden met de verpleegkundige agenda voor rehabilitatie en herstelondersteuning door te laten zien hoe verpleegkundigen en andere zorgverleners de sociale context van het foto-instrument kunnen gebruiken om het moreel leren te bevorderen. Moreel leren omvat het oppakken van verantwoordelijkheden door patiënten, bijvoorbeeld de rol van de vader door William en in het geval van Benny het inzicht dat succes in het leven alleen bereikt kan worden door daarvoor stappen te zetten om je zelf te ontwikkelen en verantwoordelijk te zijn voor je eigen leven.

In hoofdstuk 5 hebben we ons gericht op de perceptie van patiënten van de impact die een psychische stoornis heeft op hun dagelijks functioneren. Uit studies over stigmatisering (Corrigan & Watson, 2002; Hinshaw, 2007; Link et al, 1989; Wright, Gronfein & Owens, 2000) weten we dat patiënten op verschillende manieren reageren op stigmatisering:

1. door zelfstigmatisering als gevolg waarvan de zelfwaardering afneemt
2. door gerechtvaardigde woede die hen motiveert om actief te worden in initiatieven tot collectieve belangenbehartiging en andere acties voor empowerment
3. door ongevoelig te blijven voor de invloed van een stigma

Tegelijkertijd concludeerden we dat er nog steeds veel onbekend is over hoe mensen een leven met een geestesziekte ervaren. We gebruikten in deze deelstudie een design van *mixed methods* om uit te zoeken hoe het foto-instrument de perceptie van deelnemers beïnvloedde met betrekking tot de impact van ziekte op het dagelijkse leven. Zagen ze na het volgen van de fotogroep een verandering in de mate waarin hun ziekte hun dagelijks leven beïnvloedde? We maten de verandering in perceptie met een vragenlijst, de Sickness Impact Profile (SIP), die we afnamen bij deelnemers in een pre-posttest design. De uitkomsten geven geen significante veranderingen in de overall scores te zien, behalve in het domein van mobiliteit. Hier was de door respondenten bij zichzelf waargenomen impact van de ziekte significant verminderd. In dit deeldomein van de SIP zijn dagelijkse taken opgenomen zoals boodschappen doen, het schoonmaken van je huis, het afhandelen van persoonlijke administratieve zaken en bezoeken aan vrienden en familie. De andere domeinen van de SIP gaan over de controle die iemand heeft over somatische en motorische functies, psychologische en (sociale) gedragsfuncties en de regulatie van emoties. Sommige van deze domeinen weerspiegelen somatische issues

die nauwelijks relevant waren voor de deelnemers in ons onderzoek. Dat zou kunnen verklaren waarom geen significante verschillen optraden in de uitkomsten in deze deelgebieden van de SIP.

Toen we een differentiatie aanbrachten tussen opgenomen patiënten en ambulante patiënten vonden we een significante afname in de groep van ambulante patiënten voor het domein van sociaal gedrag. Het betreft hier hoe patiënten de invloed zien van hun ziekte op het sociaal functioneren in relatie tot anderen (partner, kinderen, ‘anderen’ in het algemeen). Seksuele activiteit, het bezoeken aan vrienden en activiteiten in groepsverband zijn onderwerpen in deze categorie en ook huishoudelijke taken in en rond het huis en recreatieve activiteiten.

De uitkomsten van de SIP werden gebruikt om een onderscheid te maken tussen respondenten die vonden dat hun ziekte minder invloed had gekregen op hun dagelijks leven na het volgen van een fotogroep en de groep mensen die dat niet vond of dat het gelijk was gebleven. De subgroep van ambulante patiënten liet een afname zien in de perceptie van de impact van ziekte. De afwezigheid van een statistisch significante afname in de groep van opgenomen patiënten zou veroorzaakt kunnen zijn door het gegeven dat binnen de SIP-domeinen ‘mobiliteit’ en ‘sociaal gedrag’ vragen zijn opgenomen over een huiselijke situatie die veel meer de situatie van ambulante patiënten weerspiegelt dan die van opgenomen patiënten, die in een ziekenhuissetting wonen. Uit diepte-interviews met opgenomen patiënten (long stay) en hun verpleegkundige begeleiders kwam naar voren dat deze patiënten, los van een eventuele verandering in hun perceptie van de impact van hun ziekte op hun leven, een tamelijk realistische kijk hebben op hun beperkingen en hoe deze hun dagelijks functioneren beïnvloeden.

Dit leidde echter niet tot een aanpassing van het zelfbeeld in een negatieve spiraal naar beneden (met de lege identiteit van chronisch patiënt als schrikbeeld). Patiënten bleven

verlangen naar een ‘normaal’ leven waarin ze zelf keuzes kunnen maken, hun eigen huishouden kunnen runnen, betekenisvolle activiteiten ondernemen, vrienden en familie zien en misschien zo nu en dan op vakantie kunnen. In dit opzicht passen ze in de categorie die Corrigan en Watson (2002) in gedachten hadden toen ze een derde groep onderscheidden (zie hierboven) van patiënten die ongevoelig leken voor de invloed van stigma.

In therapeutische zin laten de bevindingen van hoofdstuk 5 zien dat de gelegenheid om hun verhaal te vertellen een aantal patiënten helpt om opener te worden en hun gevoelens en de situatie waarin ze zich bevinden beter te begrijpen. Deelnemers toonden tekenen van hoop en motivatie om nieuwe plannen voor de toekomst te realiseren in overeenstemming met hun mogelijkheden. De communicatie met verpleegkundigen verbeterde en een grotere openheid maakte een betere afstemming mogelijk van de zorg aan de behoeften van de patiënt.

Methodische acties die betekenisgeving in de psychiatrische praktijk bevorderen

In de laatste deelstudie hebben we onderzocht hoe het foto-instrument als professionele interventie kan worden gebruikt door verpleegkundigen en andere gezondheidswerkers.

In hoofdstuk 6 hebben we de interventie geanalyseerd vanuit een methodisch perspectief. Uit een literatuurstudie bleek dat er maar een paar publicaties zijn die verslag doen van het gebruik van hermeneutische fotografie in klinische settingen. De meeste voorbeelden vonden we in sociaalwetenschappelijk onderzoek naar beleving, soms ook van gezondheid, van personen in specifieke doelgroepen maar waar geen therapeutische doelen aan verbonden waren. Hermeneutische fotografie is geworteld in de hermeneutische filosofie. Dit komt ook tot uiting in de acties die

gezondheidszorgwerkers, bijv. verpleegkundigen, doen in het kader van de interventie. Methodisch werkt de interventie via stappen die afgeleid zijn van de twee centrale concepten: 'mimesis' en 'performance'. In de uitwerking van deze kernbegrippen zijn hermeneutische acties, groepsdynamische interventies en acties die de expressie bevorderen gecombineerd.

Een voorbeeld is het continue proces van reflectie en dialoog tussen de begeleiders van de groep en de deelnemers. Onze bevinding is dat de setting van een fotogroep door patiënten als veilig genoeg ervaren wordt om in een dialoog te treden met de begeleiding van de groep en met de andere deelnemers. Het foto-instrument faciliteert zo het proces van verhalen vertellen. Een ander voorbeeld is de hoe de begeleiding stimuleert dat deelnemers van de fotogroep naar elkaar verhalen luisteren en naar elkaar toe op een positieve wijze reageren. De tentoonstelling aan het eind van het traject verbindt de deelnemers en begeleiders aan een gezamenlijk doel. De samenwerking tussen patiënten en professionals is daarmee een van de sterke kanten van het foto-instrument en raakt aan de intentie van veel beroepen in de geestelijke gezondheidszorg om een therapeutische alliantie aan te gaan met patiënten zodat zij hun zorgen en behoeften kunnen uiten, weer hoop krijgen en een doel vinden in hun leven. Dit is nauw verweven met de beroepsmatige agenda van empowerment, belevingsgerichte zorg en rehabilitatie/herstel. Het foto-instrument kan gezien worden als een toolbox in dienst hiervan.

Indien we alles wat in dit proefschrift betoogd is, willen samenvatten komen we tot de slotsom dat uit ons onderzoek gebleken is dat het foto-instrument een geschikt interventie is voor verpleegkundigen om bij patiënten het proces van betekenisgeving te faciliteren waarmee ze ervaringen met ziekte en het lijden kunnen duiden. Breder nog

faciliteert het foto-instrument ook het maken van eigen keuzes en het oppakken van nieuwe rollen en verantwoordelijkheden. Dit hebben we een vorm van moreel leren genoemd. De samenwerking tussen patiënten onderling en met de verpleegkundige is daarbij een sterke kant van de interventie. Het foto-instrument stelt patiënten in staat om meer regie te nemen in die samenwerking. Door foto's te maken zijn ze niet langer passieve ontvangers van zorg door hulpverleners. Met hun beelden en verhalen spelen ze een actieve rol in de communicatie. Daarbij helpt de interventie patiënten zo om een metapositie in te nemen met betrekking tot hun lijden en op die manier schept ze ruimte voor reflectie. De sterke link van de interventie met het leven van alledag en haar focus op waarden, wensen en ambities zijn factoren die het proces van reflectie een positief maar realistisch karakter geven. Vanuit deze kwaliteiten kan het foto-instrument goed geïntegreerd in of gecombineerd worden met andere therapeutische benaderingen of interventies. We denken dan allereerst aan het Strengths Model in de herstelgeoriënteerde rehabilitatieprogramma's, maar ook aan metacognitieve trainingen in schizofrenieprogramma's en aan traumabehandelingen en resocialisatieprogramma's waarin een belevingsgerichte focus op het leven van alledag en de relaties tussen mensen gecombineerd worden met aandacht voor idealen en waarden. Hoe het foto-instrument zich daarmee verhoudt, is beschreven in de Discussie paragraaf.

Wilt u zelf met hermeneutische fotografie aan de slag?

Voor een nadere kennismaking met de methodische aspecten van de hermeneutische fotografie, in het bijzonder die van het foto-instrument, kunt u de volgende website raadplegen:

www.fototherapie.startje.com

Meer informatie kunt u ook opvragen bij de auteur:

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The Photo-Instrument

The manual

Introduction

The Photo-instrument is a manual or protocol for implementing a set of interventions with the medium of photography in a health care setting. It describes the stages that are needed to have patients or clients make photos of their life world. There are two rounds of 8 group sessions, that are conducted by 2 facilitators (one nurse and an occupational therapist). At the start of both rounds the participating patients get a disposable camera and an assignment that instructs them what to photograph. Photographs are made in between sessions and only in the beginning. From the set of photographs that were shot at the beginning participants proceed to compose their own individual photo story. In the end this photo story will be exhibited and shown to others outside the photo group. In this manual we describe how we use disposable analogue cameras. They have certain advantages over digital cameras: they are less vulnerable for damage because they lack functions that even simple digital cameras do have. They are therefore easier in use. A therapeutic advantage is the fixed number of photographs one can shoot. This compels participants to make choices and it makes the assignment easier to handle.

We think that the optimal size of a photo group is 6 persons, with a minimum of 4 and a maximum of 8 persons. The criterion for inclusion is that participants are no longer in the midst of a psychiatric crisis and also have left behind them the hectic feelings associated with the first period of recovery: anger, denial and possible opposition towards caregivers. On entry into the photo group their psychiatric symptoms may still be present, but these symptoms must not dominate behaviour in a manner that precludes reflection on how they can accept a certain vulnerability while still thinking on how life must go on. An exclusion criterion is a florid psychosis as this often interferes with communication and group interaction. Persons with a severe depression may profit from the intervention focus on what one values in life, but only when the group is composed of persons with diverse backgrounds and psychiatric states of mind. Especially with grave mood problems one runs the risk of self-confirmatory behaviour and of revelling in grief over all good things of value that one has lost if everyone in the group shares the same perspective of being beyond hope. This being stuck in the mud does not mean that grieving and claiming recognition for it cannot be a transitory phase during the sessions of the photo group. It is often a first step before one can get on and find the connection again with hopes and wishes.

INSERT: CLIENTENFOLDER

Figure 1: an information brochure.

First session

- Information is given about the program.
- Disposable cameras are handed out.
- Instruction in how to handle the camera.
- The assignment (appendix 1) is handed out and discussed.
- Arrangements are made for assistance and support with making photographs when necessary.
- Deadline is agreed on for handing in of disposable camera.
- Optional: for the next session participants are invited to bring with them old photographs from private albums and also their own privately-owned

cameras. Participants are asked to select photographs they are willing to tell more about.

If photographs have not yet been developed and printed then the next session will be devoted to:

- Evaluation of last week's experiences with taking photographs.
- Having an opportunity to share one or two private album photographs with others.
- Using these photographs the nurse facilitator will demonstrate how in next sessions participants will be interviewed about their photographs.

Second session

- Evaluation of experiences with taking photographs.
- Photographs have been developed and printed and every participant receives his own set of photographs.
- Taking time for a first look at photographs. First responses are shared.
- Participants spread their photographs in front of them on a table.
- Participants are invited as a group to tour around the room and admire the photographs of other participants. They are instructed to ask each other at least one question about someone's photographs. The nurse facilitator will do so too, but will shape his question in anticipation of the interview of the next session.
- The instructions that follows are:
 1. Go through your photos and group them together.
 2. Then everyone gets a large-sized sheet of photo-carton and is asked to glue the photos on to the sheet in the groups that have been selected.
 3. The next step is the request to think of a caption for every group of photos on the sheet and to write this down on a memo (the small sized blocks of sheets one uses in an office to remind you of tasks still to perform). The participants stick their memos to their groups of photos. A caption can be an emotion aroused by the picture or a topographical reference or whatever participants can make up to be the theme or the subject of the photos³.
 4. Have photographs numbered. Optional: have groups of photographs encadred with a ruler and invite participants to number the encadred groups (this makes it easier to know which photograph is referred to during the interviews).
- The nurse facilitator interviews everyone on his or her labels that were written on the memo sheets for grouping together photographs. The second facilitator takes notes of what every individual participant reports. These notes are processed in between sessions and returned as a print-out to participants in the next session.

INSERT FIGURE : AN EXAMPLE OF A PHOTOCARTON

³ When the assignment is less open, but is more pre-structured, as in the second round, then the grouping criterion will be premeditated.

Figure 2: an example of a photo-carton used as a worksheet.

Third (and when necessary fourth) session

- Every participant puts his photocarton with photographs on the table in front of him. The nurse facilitator explains the procedure: photographs will be selected from every group of photographs. These are the photographs which show best the intention of the photographer to picture a theme as formulated on the memo sheets. The nurse facilitator explains that a further selection will take place during the next sessions in order to get a set of photographs that will tell a story and which can be used for a photo exhibition.
- Participants are invited to choose one picture per group, namely: the picture that matches best the chosen group caption. The choice is then made visible by attaching a memo-sheet to the picture.

Nota bene:

Why not ask for the best photograph in stead of asking for ‘the photo that matches best the label’? Asking for the best photo invites the participants in selecting photos that conform to standards of technical or aesthetical quality. That’s not what we go for. Even unsuccessful shots, for instance blurred photos that are technically unsatisfactory can be relevant because of the meaning that the photographer project in what’s been depicted.

- When the selection has been done we start rounds of interviewing the participants on their choices. Everyone gets a turn. The relevant things the participants tell about the photos are noted down by one of the two group facilitators.

Questions to be asked are:

- What can be seen on the picture?*
- What does the picture mean to you?*
- What makes this photo special for you?*
- What does this photo (or what is been depicted in the photo) stand for?(explore)*
- What is the situation that we can see in the picture?*
- which other picture belongs with this picture?(compare)*
- In what respect do the two pictures agree or differ?*
- What picture shows best what you intended to tell us?*
- Is there another picture that shows an opposite meaning for you?*
- Are there pictures you wanted to make but couldn't and for what reasons?*

Nota bene:

Use a build-up in interviewing: go from the more concrete level of what can actually be seen on the photos (who is portrayed, what objects, animals, setting, etc are photographed) to the level of what the portrayed persons or the objects, animals etc. photographed mean to he person who made the pictures. Explore this meaning. From this level you can try and probe even further (see appendix 2) to find out what motivates and drives the photographer in life, or more passively, when the photo depicts or refers to a situation he or she lives in:

- What consequences are there for you?*

-How do you cope with this situation?

-Can you give other examples of this situation or how you cope with it?

From this level you can try and step over to the level of fundamental values, ethical norms or basic principles and beliefs. Not everyone will be able to verbalize what he or she believes to be a fundamental value. Sometimes you as interviewer can help the photographer by summarizing and checking whether this is what he or she tries to say, or by reformulating it in more intelligible words (note of caution: be aware of crossing the line where you impose 'fine answers' on respondents who want to oblige you and therefore don't protest).

Remember that the actual photograph and that what it depicts grounds the interview. Don't hesitate to go back to the realities of the material world and the lived experience associated with it when the photographer goes astray and wanders off in speculations and fantasies. When you notice that your respondent explains his photographs in vague or abstract terms, then ask him to illustrate what he means with examples (here you reverse the build-up from the concrete situatedness to more abstract and instead step down from the aloofness to what it means more practically).

Be careful with 'why'-questions as these tend to stop the exploration and ask for accounting. People often feel forced to take a stand and that is likely to shortcut further reflection. Moreover people feel uncomfortable when asked why they think this or that and want to get away from the situation. They will easily answer in a desirable manner, just to have the asking done and over with. When you notice this, then avoid the why-question and use another formulation, for instance: 'what does this photograph mean to you?'

- The facilitators stimulate interaction between group members by creating opportunities to put forward questions to fellow group members or to comment on photographs (however, negative qualifications are not allowed).
- A new assignment: everyone gets a set of so-called emotion cards (small cards with one word referring to an emotion. On the reverse side the opposite meaning). Every participant is invited to select a number of cards and match them with photographs. The cards are put down on the photocarton beside the photographs.

Titles on the emotion cards:

Cosy	Hostile
Safe	Unsecure
Confidential/intimate	Unprotected
Happy	Sad
Harmonious	Unbalanced
Comforting	Lonely
Caring	Uncaring
Warm	Reserved
Trusted	Strange
Funny	Dull
Exciting	Boring
Calming	Unsettling

Proud

Shameful

- Every participant is invited to elaborate on his or her choice why a certain emotion card matches a particular photograph. One of the group facilitators takes notes of the participants' responses. The procedure can be repeated with more photographs. If one of the emotion cards with 'shameful' is used, then the facilitator asks why this photograph evokes shame.
Optional: Participants are invited to see one of their photographs as a movie still. Questions to be asked are: what movie is the still part of? Which scene is filmed here? Imagine that you can step into the photograph (or into the movie): what is it that you hear, see, smell and feel now? Facilitators take notes of what is been said, process these notes in between sessions and then return them to participants the next session.

INSERT FIGURE 3: EMOTION-CARDS

Figure 3: an example of (a fragment of a) photo-carton with emotion-cards attached to a photograph.

Fifth and sixth session

- The assignment is now to select three pictures for an exhibition. The nurse facilitator discusses with participants aspects of representation they should take into account, for instance are they aware of any consequences of sharing certain private feelings with a greater public? Text can be adjusted. Some participants may be inclined to disclaim what they have said earlier and use instead 'safe' but may-be less authentic or relevant text fragments. Although the participants determine which photographs and accompanying story will be selected for the exhibition, it remains important to keep up the dialogue and find out whether feelings of shame make a participant withdraw photographs and text and if so, whether there is no other way of coping than avoidance.
- Participants may write an introductory text in which they tell who they are and why they participated.
- Text will be printed and used as captions with the photographs

Seventh session

- The enlarged photographs are handed out and participants frame them themselves.
- This meeting can be used to share the preparations for the exhibition:
 1. Designing and printing of invitations
 2. Writing the text for flyers
 3. Designing announcement posters
 4. Preparing the exhibition: arranging the photographs and photo stories in good order on exhibition room walls. Arraying one or two photo cartons (worksheets) on a table because this is instructive as far as the followed process is concerned.
 5. Every participant will be the host for invited visitors who like to be guided in admiring his or her particular photo story. This performance can be practised in the 7th session.
 6. Delivering an opening speech at the opening night: use this session as an opportunity for practising.

7. The facilitators invite volunteers for an interview in the news organs of the institution or the local press.
8. Arranging who is going to make photographs during the opening night.
9. Taking care of the catering: who bakes a number of cakes for the invited visitors; who will tend to the guests and provide them with coffee and tea?

All these tasks can be collectively done and are part of the project. Nurse facilitators stimulate participants to make an active contribution to the organisation of the exhibition.

INSERT FIGURE 4: AN ANNOUNCEMENT POSTER

Figure 4: an example of an announcement poster.

Eighth session: the opening night of the exhibition

- The exhibition itself is the 8th session.
- The exhibition can be formally opened. The participants guide the visitors along their pictures. Some of them have taken upon them to do the catering.
- Beside personal guests for every individual participant there may be officially invited guests: members of the board, management, client council representatives, etc.
- An opening speech. The nurse facilitator may start with some words on backgrounds and goals of the photo group and then invite one of the participants to tell how he/she has experienced his or her participation.
- Another participant will ask visitors to write their impressions in a visitors' book.
- An extra possibility is to have collected all photo stories for publication in a book. This is then presented at the opening night of the exhibition.
- The group facilitators thank participants for their hard work and 'reward' them by
Giving each of them one single rose.

Not bene:

Pay attention to the following aspects:

1. Take care that you can receive visitors in another room than where the photographs can be seen.
2. Do not have participants show around their guests before the opening speech. Request visitors to return to the reception hall after having been showed around. Here they can have a drink and a bite and there will be an opportunity for exchanging reflections and ask questions. Facilitators can use this occasion to highlight positive responses, thus maximally reinforcing participants for the courage and openness to share their life world with us.

INSERT FIGURE 5: THE PHOTO-EXHIBITION

Figure 5: The photo-exhibition.

Ninth session: evaluation

- Evaluation of the exhibition.
- Evaluation of the project.
- Sharing and admiring of photographs taken on the opening night.
- Information and warming up for the second round.

Second Round

The same participants are present again. Some participants may have decided not to partake in this round. Others have been dismissed from hospital. It always remains possible to partake in a second round at a later time. The assignment in this round is more difficult, requiring more imagination from participants than in the first round. The assignment now focuses on an anticipation of someone's future. This may be too much a challenge for some participants who do not dare to think beyond the here and now, because the present is already very much threatening. For other participants however thinking of the future may work as an anchor, giving them the support to survive the present. The assignment has been formulated with options to contain both groups. There are two more group of participants that need special attention. One of them is the group of participants who are so depressed that they may seize upon the assignment to picture their life in sombre and dark images. Images of death, symbolizing suicidal intentions for instance, however much we may understand where they come from, are highly disquieting and alarming for fellow group members. Within the context of the photo-instrument it would be extremely difficult to handle self-defeating and nihilistic messages and contain them. More psychotherapeutic interventions would be needed for which there is no room within the context of the photo-instrument. This is not what the photo-instrument is intended for. The assignment stimulates hopeful thinking and the longing for a better, healthier and happier life. Where a participant presents images that breathe despair or deep sorrow or a focus on losses, the nurse facilitator will always invite the participant to look for other photographs in which he or she finds consolation and that support him/her to carry on in life.

The other group that needs attention is the group of patients who still suffer from a florid psychosis. They have too many problems with structured thinking and working together with others to profit from participation.

The second round follows the same procedures as the first round, but some things are different. We will focus on these differences mainly.

First session

- The assignment is handed out. This session we will focus on part one of the assignment: images of the future.

Assignment: Images of the future

How do you wish your life to be in 1 or 2 years' time?

⇒ • **Choose option a or b**

a New things:

Whom do you hope to have become then?
What do you hope to have attained?

or

b Keeping the old (valuable) things and throw away problems/burdens:

Which good things from the here-and-now do you want to keep and take with you to your future?
Which problems and trouble do you hope to have left behind you in two years' time?

- ⇒ • Try to make a mental image of this.
- ⇒ • Then find a way to picture this image in a photograph. Maybe you need to stage the role or person you want to become. Maybe you will find it necessary to go somewhere else to make photographs as you intend to work there in the future, live there or follow an education.
- ⇒ • If you choose for keeping the good old things, then make photographs of these things and also of problems and trouble you want to dispose of. But also wonder how your world looks like without these problems. How would you notice that things have changed? Make at least one picture of this new reality.

2. The group facilitators give examples of how participants can use attributes to stage an image of a wished for future, which otherwise would be difficult to visualize because our expectations of the future are sometimes abstract and diffuse. The group facilitators organize a brainstorm-session with participants to

share possible solutions to the problem of staging one's future. They share with participants photographs from magazines that illustrate how to picture an emotion or a professional role. Have these photographs go around among participants and have them write down what their interpretation is of what they see. Emphasize that every individual may recognize something else in the same photograph and that these interpretations are all true. Explain that photographs need amplification to make clear what the photographer meant to express with them.

3. Participants who find it threatening to anticipate their own future can be directed into the option of keeping the good things of the present.
4. Participants are handed out a sheet on which they can fill out key words related to their images of the future. This is a kind of outline with four columns: one column for one or two wishes or images of the future and for every wish one row specifying skills, obstacles and sources of support (these cells will be filled out during sessions of the next weeks).
5. The nurse facilitators invite participants to exchange their images of the future. One question is leading: how will you picture the image into a photograph? All group members can contribute their ideas on this how-to-do question. Participants make notes of these practical advices on their outline. This outline then becomes a guiding plan for the actual photographing action in between sessions.
6. The assignment for next week is: make 7 photographs of how you imagine your future will look like (wishes). The remainder of the photographs of the film roll will be used when part 2 of the assignment comes up for consideration.

Outline as aid with the assignment: filled out by participants.



Images of the future: goals and wishes	What do you need for realizing? (part 2 of the assignment)		
	Skills and talents	Obstacles	Resources?
1:.....	1	1	1
Execution/performance:	Execution:	Execution:	Execution:
2.....	2	2	2

.....			
Execution:	Execution:	Execution:	Execution:
3.....	3	3	3
Execution:	Execution:	Execution:	Execution:
4.....	4	4	4
Execution:	Execution:	Execution:	Execution:

- Two weeks are reserved for doing the whole (part 1+2) assignment (execution). In the third week the cameras are handed in. This may seem a relatively short time, but it compels participants to make choices and set an agenda for making photographs. Take notice of the fact that developing and printing photographs may result in delay if you do not reckon with it in your planning.

Second session

- Evaluation of how everyone got along with the assignment. Experiences are exchanged. If necessary part of this session can be used to get help from other group members for making photographs that need attributes or a staging of a scene to picture the image someone had in mind. In this way group members learn to share things.
- In the same way as was done for part one of the assignment part two is discussed and explained:
 - examples are given.
 - ideas how to make photographs are exchanged.
 - the group facilitators hand out photographs that illustrate how a message can be interpreted.

-outline sheet: all the remaining rows and columns are filled out now by participants.

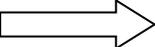
As the assignment is rather complex and may have an emotional impact upon participants, facilitators can decide to ask participants to select only one image of the future or wish and work this out in what one needs to realize this goal or wish. The selection of the image or wish must be done on the basis of what someone has written down and the memory of which photographs were made as the camera is not yet handed in and prints of photographs are not yet available (with digital photographs this would not pose a problem). The assignment for the coming week will be now to photograph what it takes to realize one's wish or goal.

Part 2 of the assignment:

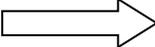
What do you need to realize your wish?

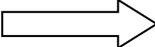
To realize your wish or attain your goal you may need certain skills. Skills that you may already possess or that you still need to learn. May-be there are certain talents or personal qualities that are necessary to attain goals that you wish to happen in the future, for instance perseverance to hold out against set-backs. There may stand obstacles in your way that has to be dealt with first, for instance improving your physical condition. Other people will be needed to help you. They are resources for help and support in your efforts to realize your wishes.

Select from below two (not more) items that apply to the image of the future/wish you have chosen. This will direct the photographs you are going to make the coming week.

 **Skills and talents** you need for realizing your wish?

Try to find an image that fits the necessary skills and talents. What is it that you see in your mind? Can you put it in a photograph?

 **obstacles**

 **resources**

You can, if you want to, make photographs of all three items, but two will also do, for instance: **skills/talents and **obstacles** or **skills/talents** combined with **resources**.**

Outline form: for participants to fill out. One row has been shaded. This is the row that can be selected. Some participants will go for more wishes to photograph and then need more rows to fill out. This outline form is an aid for the actual photographing exercise.

Images of the future:	What do you need for realizing? (select the cells and fill them out)
------------------------------	---



goals and wishes			
	Skills and talents	Obstacles	Resources (support you get: from whom?)
1:.....	1	1	1
Execution:	Execution:	Execution:	Execution:
2:.....	2	2	2
Execution:	Execution:	Execution:	Execution:
3:.....	3	3	3
Execution:	Execution:	Execution:	Execution:

- Group facilitators make a copy for their own registration. Mark which rows participants decided to make photographs of.
- Week 2 will be used for ‘**What do you need for realizing this wish?**’ In week 3 the camera will be handed in. Some differentiation is possible in how much effort participants put into the photographing when you allow eager participants to select more than one row in the outline.
- Facilitators arrange individual help and support in between sessions when necessary.
- If skills and talents seem unrealistic then group facilitators will enter upon a dialogue with the participant to find more concrete and more realistic terms.
- Participant who have limited themselves in part 1 to the option of ‘keeping good old things and throwing away problems and trouble’ may find it difficult to formulate skills and talents in part 2 of the assignment. Keeping things takes no special effort. Part 2 is much more focused on the option of ‘new things’. That is why participants must be urged in part 1 to make at least

one photograph of something ‘new’: a yet unknown aspect of the reality they wish for.

- Participants may mention obstacles that have to do with being hospitalized, for instance: side-effects of medication, certain limitations of residential living. Then it may be necessary for group facilitators to try and steer participants to obstacles that lie within their reign of influence to make a change. The same goes for skills and talents if participants have an unrealistic idea of what is needed to realize a certain wish or attain a certain goal. For instance: making a lot of money while someone has a lot of trouble to keep a job. Another aspect that deserves attention is that sometimes rather vague and general or abstract skills and talents are mentioned. These are often difficult to picture. Then it is advisory to help participants to translate them into concrete situations, for instance by asking them how perseverance looks like in their particular situation. Sometimes it is better to transform skills/talents or obstacles in an intermediary goal that first must be met before one can go on with the higher goal that lies more far away.
- Group facilitators fix the number of photographs for the shooting in between sessions: for instance 10 for skills/talents and 5 for obstacles and 5 for resources (if all three items have been selected).

INSERT FIGURE 6: HUISKAMER DIDAM

Figure 6: a session of a photo group.

Third session

- Evaluation and exchange of experiences.
- If necessary participants use this session to make photographs they found difficult to make at home. The camera will be handed in at the end of the session.
- In between the third and fourth session the cameras are sent to a photoshop to be processed.

Fourth session

- The photos are returned to the participants and the group shares in collectively admiring of the pictures.
- Participants are invited as a group to tour around the room and admire the photographs of other participants. They are instructed to ask each other at least one question about someone’s photographs.
- Photographs are sorted and grouped together. The criterion for grouping is the selected wish from the second session and the adhering skills/talents, obstacles and resources. The photocartons can be prepared to this aim with a grid that resembles the outline sheet.
- Labelling: the catchwords from the outline sheet can be used here. Have the catchwords written on the photocarton.

Fifth session

- Prioritizing of photographs by participants: which photograph in each category (images of the future-skills/talents-obstacles-resources) is the most meaningful? Mark these photographs. ‘Most meaningful’ must be understood as: which photograph shows best the necessary skills and talents to realize the selected wish or image of the future. And which photographs of obstacles and resources suit this train of attribution? For example: getting one’s driving licence (wish); skills needed for getting a driving licence are concentration and perseverance. Obstacles may be: use of medication and an inclination to give up when one is confronted with setbacks. The support that someone gets may come from one’s best friend or one’s parents.
- Preparing for the exhibition: fixing a date, making a list of the invited guests, designing an invitation, etc.

Sixth session

- Group facilitators interview every participant. They invite participants to explain the selected photographs in terms of the imagined wish or goal, the necessary skills/talents, the obstacles that must be overcome and the support needed. Facilitators try to proceed from the concrete aspects (what can we see in the photograph?) to the functional characteristics (what goal/wish does the image represent, what skills, obstacles do the pictured objects and persons refer to?) and from there facilitators can explore what it all means to the participant on a psychosocial level. This eliciting of meanings is done in an explorative way by *probing* (see appendix 2). Questions may be:
 1. How do you think you will cope?
 2. What does it mean for you?
 3. Can you give examples of this..?

The frame for this in-depth interviewing is the set of photographs that participant had selected in last session:

Future wish/goal---what do you need?---obstacles---resources.

The facilitator may steer the interview into the direction of connecting these distinct factors. For example: to make concrete the relation between the support offered by relatives and the wish to improve one’s physical condition the group facilitator can go into more depth by asking *which* relative does *what* at *what* moment to support the participant in his wish. The participant’s answers may evoke a dialogue on how realistic the final goal will be if the expected support is not certain. In this dialogue it may turn out that it may be wise to identify the support of relatives as an intermediary goal. The facilitators must manoeuvre here between too much steering/directing on the one hand and too much letting go that would allow participants to build castles in the air.

- Facilitators invite other group members to respond to each other.
- Still not attended to is the practical issue of what participants think that they must do to acquire the necessary skills, neutralize obstacles, gain support from others, etc. Therefore the group facilitators now ask participants to formulate where the challenge is in it all. What challenge is there for you in wanting this wish to become reality? How do you go about it? What steps lay waiting? How do you tackle this challenge? For instance: how do you set about improving your concentration skills when you want to take your driving licence? In dealing with the issue of challenge participants must

formulate concrete actions that land their story on the ground. The assignment to formulate what challenge their story poses is prolonged and stretched out into the next session. Participants are invited to take the assignment home and reflect on it for a while and to discuss the issue with a mentor nurse or their psychiatrist. Thus we contribute to embedding the process of meaning construction into the agenda of treatment and support. Facilitators write down the things that participants tell and process them in between sessions. These notes are returned the next session.

- Invitations are written. Participants are invited to volunteer for designing announcements.

Review Form for group facilitators.

<p>Statements by participants:</p> <ol style="list-style-type: none"> 1. write down statements per photograph 2. mention the number of the photograph and give a short description of the photograph
<p>Which set of photographs (row in the outline scheme)) are described? (images of the future-skills/talents-obstacles-resources)</p> <p>Row 1:</p> <p>Row 2:</p> <p>Row 3:</p>
<p>Which set (row) of photographs is selected for further reflection and making statements? What is told about these photographs?</p> <p>Image of the future (wish or goal) :</p> <p>Skills, talents or qualifications:</p> <p>Obstacles:</p> <p>Resources:</p>

The challenge (short summary):

INSERT FIGURE 7: POSTER GROENLO

Figure 7: an announcement poster

Seventh session

- Printed text from interviews is returned to participants. These text lines are checked, and then glued beside the photographs on the photocarton.
- Group facilitators invite participants to report on their reflections and discussions with mentor nurses and psychiatrists concerning the challenge that their photo stories pose. Facilitators take notes of participants' answers. Depending on cognitive skills the assignment can be extended to inviting participants to write a short essay (appendix 3).
- A set of photographs is selected for enlargement with a maximum of 5 photographs.
- Participants are invited to select text lines as captions with photographs. Facilitators are asked to take into account for whom the message is intended, what the impact will be on viewers and whether there is confidential information that is not meant for a larger public. Text lines can still be changed.
- Participants work on practical issues related to the exhibition: announcement posters, introductory text with which every participant present himself, etc.

Eighth session

- Framing enlargements.
- Facilitators return printed latest versions of text.
- Participants glue text lines on carton and plasticize them (to go with the encadred photographs).
- Introductory texts are framed and plasticized.

- Announcement posters are talked over and approved of.
- A visitors' book is made.
- Tasks and roles for the opening night are divided among participants.

INSERT FIGURE 8: EXHIBITION PHOTOS PRESENTED AS A POSTER

Figure 8: an example of how participants' photographs and text can be presented in a more creative style.

Ninth session (on the same day as the opening night)

- Last things are looked after.
- Photographs are put up together with captions, introductory text and announcing posters.

Appendices

Appendix 1: the assignment for the first round (first 8 sessions)

Make photographs of things of value in your life. That can be next of kin or friends, but not necessarily. You can also make photographs of objects and animals that have a special meaning to you. Making photographs of places is also possible. If it is not possible to make photographs of the actual thing then you can also make a sketch or a drawing that represents it and then make photographs of it. Or photograph something that symbolically represents what otherwise is difficult to make pictures of.

Good luck!!

Appendix 2: Probing, prompting, summarizing and limiting participants

Probing, no prompting: facilitators stimulate participants to explore meaning constructs at further length in stead of looking for confirmation of what the interviewer thinks that participants mean. That's why we prefer open questions.

For instance:

1. Can you tell me more about...?
2. How does it feel to be...?
3. What does it mean...?
4. What are your experiences with...?
5. What happens with you when...?
6. What are the things that you have to cope with when..?
7. On which occasion did you experience this?

Closed questions can often only be answered with yes or no. Explorative questions (*probing*) invite participants to open up and consider more than one perspective. *Prompting* 'freezes' the participant as he/she must confirm an expected answer. It focuses attention on assumptions and hypotheses of the interviewer. Participants will often feel resistance when prompted. If he/she goes along then the result reflects the way of thinking of the interviewer and not of him (her)self. Even if the interviewer and the participant are of one mind then still the urgency and relevance of the issue will probably be different. Prompting should not be confused with summarizing. The group facilitator may need to summarize a discursive speech. Then he/she will ask the participant if his/her summary is correct.

It is far more likely that participants have to be limited than to be stimulated. Some participants are inclined to tell more than they can handle emotionally (and then regret having told so much) and/or people around them can tolerate. This is especially the case with sensitive emotional issues that touch and may-be distress other participants, because they have experienced the same in their lives. If participants are confronted with stories that are emotion-laden for them, they may resent this. If so, then participation in the photo group may become 'heavy'.

This would detract from the joy of story-telling and sharing of photo stories. The group facilitators must adopt a middle course here: it is okay to tell difficult 'heavy' experiences in which participants mourn over losses they have incurred in their lives, but these experiences should not set the tone. The assignment is to make photographs of things important and dear to you, with the intention to find strength in them. The group facilitators must therefore be keen on signals from group members who think that the stories of other participants come too close or are too intrusive. How can facilitators steer this in a good direction? In the first place they can remind participants that the focus is on experiences and strengths that help you to find your way in life. In the second place group facilitators can limit participants if they elaborate too much on aspects of loss and bereavement. For example: a woman tells how important her children are to her, but that she cannot take care of them and that they are placed in a foster family. It turns out that other participants share this experience with her, but are unwilling to talk about it. It is advisory here to put the brakes on her when she wants to elaborate on how things in her life have led up to her sorrow. Facilitators can ask her at a certain point in her story to leave it at that and if necessary tell more about it next week. This is dosing the message and in this way we also protect her from over-exposure.

Appendix 3: the challenge

An assignment for an essay

Take the photographs that are enlarged.

- What is the story they tell?
- What challenge does the story pose?
- What actions are you going to undertake?

Use 500 words at a maximum

Do not forget to write down your name.

Did you consider a title for your essay?

Dankwoord

Wat ooit begonnen is als een actieonderzoek in de opleiding tot verpleegkundig specialist, groeide uit tot een heus wetenschappelijk onderzoek. Dat ging niet zomaar. Op de juiste momenten zijn er mensen geweest die er iets in zagen. Ik was in 2003 in dienst getreden bij GGNet: 50 % als onderzoeker en 50 % als verpleegkundig specialist. Ik kreeg toen de ruimte om de door mij ontwikkelde interventie te gaan onderzoeken. De medewerking en de ruimte om in de tijd van de baas hieraan te werken heb ik al die jaren zeer gewaardeerd. Daarvoor wil ik het bestuur van GGNet en het management graag bedanken!

Ik denk bij het begin ook terug aan hoe Eric Noorthoorn mij in contact bracht met prof. Joost Baneke aan de Universiteit Twente en we daar met z'n drieën gesprekken hadden over mijn onderzoek zonder dat ik direct doorhad dat ik vastzat aan een promotietraject! Eric, bedankt voor dat duwtje in de rug en natuurlijk ook voor alle steun en begeleiding die je als senioronderzoeker en collega mij geboden hebt! Je hebt wel geen kwantitatief onderzoeker van me kunnen maken, maar ik hoop dat je me dat kunt vergeven.

Nou ja, toen ben ik maar begonnen. Via Eric kwam ik in contact met René de Veen, psychiater bij Mediant en Hans Poelert, manager. Zij wilden op Helmerzijde wel een fotogroep starten en vonden het onderzoek ook prachtig. Hun enthousiasme droegen ze ook over op Anne Lenderink, activiteitentherapeute en Mareike Eillert, verpleegkundige die samen de fotogroep gingen draaien. Ik heb goede herinneringen aan onze samenwerking en de betrokkenheid die jullie toonden. Hiervoor wil ik jullie bedanken! Anne, jammer dat je nu met pensioen bent en dat we niet nog een keer samen naar het internationaal congres over fotherapie in Turku kunnen!

Ook bij GGNet kwamen fotogroepen van de grond. Iedereen die daar een rol in heeft gespeeld, dank ik voor hun inzet. Speciaal noem ik hier Carla Driessen, die als verpleegkundige op locatie Het Karrewiel in Didam met hart en ziel zich inzette voor de fotogroep. Haar inzichten en praktische oplossingen hebben mijn denken over de methodische kanten van de interventie verrijkt. Dank je wel, Carla!

Behalve bij GGNet en Mediant gingen er fotogroepen draaien bij ProPersona (toen nog Gelderse Roos) in Ede, de RIBW in Enschede en de RIBW Oost-Veluwe in Apeldoorn. De medewerking van managers en verpleegkundigen maakte het mogelijk dat ik mijn onderzoek kon voortzetten. Ik wil jullie daar langs deze weg allemaal nog voor bedanken!

Maar in de eerste plaats past hier een dankwoord voor de deelnemers aan de fotogroepen die mij inzage gaven in hun gedachten- en gevoelswereld, het niet erg vonden dat ik hun foto's gebruikte voor mijn onderzoek en dat ik als onderzoeker bij de bijeenkomsten aanwezig was, ook op de intieme momenten waarop zij zich blootgaven met persoonlijke mededelingen! Ik heb dat als een voorrecht ervaren en heb vaak jullie openheid en moed bewonderd! Heel erg bedankt!

Ik sta hier ook stil bij de steun die ik ervaren heb van mijn promotoren Tineke Abma en Guy Widdershoven. Naast mijn waardering voor hun inhoudelijk meedenken, gaat mijn dank ook uit voor de bemoedigende woorden op zijn tijd, de juiste toon waardoor je je

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