
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 and are now 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 belong 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 ownership 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 '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 story-telling. 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:

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