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

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.
Chapter 5

Design
In the present study we used a sequential exploratory design with mixed methods by first analysing quantative 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 quantative 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 who 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 divided the patients into 3 categories:
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
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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 were 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 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 would 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 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 performed 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). For reasons of small numbers residual gain could not be calculated.

Differentiation into residence status was relevant because in the photo groups we included participants from very diverse backgrounds that ranged from elderly people who 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 also 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.
### Table 1: Scores for the Sickness Impact Profile Questionnaire (SIP) in a pre-and posttest design

<table>
<thead>
<tr>
<th>Dimensions of SIP</th>
<th>Inpatients T1</th>
<th>Outpatients T1</th>
<th>Total T1</th>
<th>Inpatients T2</th>
<th>Outpatients T2</th>
<th>Total T2</th>
<th>Inpatients T3</th>
<th>Outpatients T3</th>
<th>Total T3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=32 (Mean (CI))</td>
<td>N=42 (Mean (CI))</td>
<td>N=74 (Mean (CI))</td>
<td>N=34 (Mean (CI))</td>
<td>N=13 (Mean (CI))</td>
<td>N=47 (Mean (CI))</td>
<td>N=22 (Mean (CI))</td>
<td>N=26 (Mean (CI))</td>
<td>N=48 (Mean (CI))</td>
</tr>
<tr>
<td>Somatic autonomy</td>
<td>0.63 (0-2.04)</td>
<td>0.71 (0-2.38)</td>
<td>0.68 (0-2.23)</td>
<td>0.88 (0-2.27)</td>
<td>0.08 (0-0.36)</td>
<td>0.66 (0-1.90)</td>
<td>0.86 (0-2.25)</td>
<td>0.31 (0-1.10)</td>
<td>0.56 (0-1.69)</td>
</tr>
<tr>
<td>Motor control</td>
<td>1.84 (0-4.37)</td>
<td>1.10 (0-3.45)</td>
<td>1.42 (0-3.89)</td>
<td>1.71 (0-4.64)</td>
<td>0.54 (0-1.74)</td>
<td>1.38 (0-3.99)</td>
<td>2.14 (0-4.92)</td>
<td>1.04 (0-3.09)</td>
<td>1.54 (0-3.99)</td>
</tr>
<tr>
<td>Psychological autonomy</td>
<td>3.09 (0.46-5.72)</td>
<td>3.12 (0.35-5.89)</td>
<td>3.11 (0.42-5.80)</td>
<td>3.21 (0.44-5.98)</td>
<td>2.46 (0.09-4.83)</td>
<td>3.00 (0.34-5.66)</td>
<td>2.50 (0-5.20)</td>
<td>2.19 (0-2.3)</td>
<td>2.33 (0-2.6)</td>
</tr>
<tr>
<td>Social behaviour *</td>
<td>4.47 (1.52-7.42)</td>
<td>4.57 (1.21-7.93)</td>
<td>4.53 (1.36-7.70)</td>
<td>4.26 (0.99-7.53)</td>
<td>2.92 (0.11-5.73)</td>
<td>3.89 (0.71-7.07)</td>
<td>4.68 (1.25-8.12)</td>
<td>2.65 (0.5-7.2)</td>
<td>3.58 (0.24-6.92)</td>
</tr>
<tr>
<td>Emotional stability</td>
<td>1.63 (0.13-3.13)</td>
<td>1.14 (0-2.55)</td>
<td>1.35 (0-2.81)</td>
<td>1.38 (0-2.80)</td>
<td>1.15 (0-0.29)</td>
<td>1.32 (0-2.66)</td>
<td>1.09 (0-2.36)</td>
<td>0.81 (0-1.91)</td>
<td>0.94 (0-2.11)</td>
</tr>
<tr>
<td>Mobility range **</td>
<td>1.50 (0.02-2.98)</td>
<td>1.38 (0-3.31)</td>
<td>1.43 (0-3.17)</td>
<td>1.44 (0-3.37)</td>
<td>1.15 (0-2.56)</td>
<td>1.36 (0-3.15)</td>
<td>0.86 (0-2.25)</td>
<td>0.92 (0-2.44)</td>
<td>0.90 (0-2.35)</td>
</tr>
<tr>
<td>SIP</td>
<td>13.16 (4.19-22.13)</td>
<td>12.02 (1.44-22.60)</td>
<td>12.51 (2.64-22.38)</td>
<td>12.88 (1.55-24.21)</td>
<td>8.31 (1.86-14.76)</td>
<td>11.62 (1.27-21.97)</td>
<td>12.14 (2.02-22.26)</td>
<td>7.92 (0-16.02)</td>
<td>9.85 (0.62-19.08)</td>
</tr>
</tbody>
</table>

Values are expressed as Mean (CI).

* P< 0.05, ** P< 0.05
Table 2: frequency, average age, sexe ratio and diagnoses according to residence status in patients included at the start of the study. N=74

<table>
<thead>
<tr>
<th>Variables</th>
<th>Acute and short stay</th>
<th>Long stay</th>
<th>Total inpatients</th>
<th>outpatients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>9</td>
<td>23</td>
<td>32</td>
<td>42</td>
<td>74</td>
</tr>
<tr>
<td>Average age (range)</td>
<td>35</td>
<td>45</td>
<td>42</td>
<td>42</td>
<td>42</td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>11</td>
<td>14</td>
<td>15</td>
<td>29</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>12</td>
<td>18</td>
<td>27</td>
<td>45</td>
</tr>
<tr>
<td>Main diagnosis: schizophrenia related</td>
<td>6</td>
<td>12</td>
<td>18</td>
<td>12</td>
<td>30</td>
</tr>
<tr>
<td>Main diagnosis: mood disturbances</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Main diagnosis: personality problems</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Diagnosis: other</td>
<td>1</td>
<td>8</td>
<td>9</td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>Missing diagnoses</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

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).

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

<table>
<thead>
<tr>
<th>perception</th>
<th>mobility range</th>
<th>overall SIP</th>
</tr>
</thead>
<tbody>
<tr>
<td>reduction in impact</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>same level</td>
<td>32</td>
<td>36</td>
</tr>
<tr>
<td>increase in impact</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

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):

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

<table>
<thead>
<tr>
<th>Perception of impact of illness</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>reduction in impact:</td>
<td>2</td>
</tr>
<tr>
<td>increase in impact:</td>
<td>2</td>
</tr>
<tr>
<td>same level:</td>
<td>4</td>
</tr>
</tbody>
</table>
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. the striving of patients for a higher level of functioning
4. mention by patients 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 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 everyday 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.”

Therefore, 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. Similar was the case with other patients. 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] 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, according to 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 who 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 subsequent 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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Literature


Living with severe mental illness: perception of sickness


