

EXAMENSARBETE

Anorexia Nervosa:

Vad gör att patienten mår bättre?

Anorexia Nervosa:

What Makes Patients Feel Better During the
Illness and the Process of Recovery?

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Akvile Drungaite

Handledare: Agneta Widell Johansson
Examinator: Kerstin Ternulf Nyhlin

ABSTRACT

Title: Anorexia Nervosa – What makes Patients Feel Better During the Illness and the Process of Recovery?

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Author: Drungaite, Akvile

Supervisor: Widell Johansson, Agneta

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Objective: When caring for a patient with Anorexia Nervosa (AN) it is difficult for the registered nurses to develop a good nurse-patient relationship due to a lack of understanding for the illness. It is important for the nurse to understand the suffering that the AN patients experience, and what makes them feel better, to be able to improve the patient-nurse relationship. This study aims to explore what makes patients with AN feel better during the illness and the process of recovery.

Method: A qualitative scientific approach was used. Eight autobiographies were selected as data for this study. Both English and Swedish books were used. The data was analyzed using a qualitative method of data analysis.

Results: The ways patients with AN could feel better are presented in seven themes: being seen as a whole individual behind the illness, being able to trust and find security, taking responsibility for recovery, finding motivation to keep fighting towards recovery, when one's suffering is noticed, filling a void, and the strengthening of the relationship between care giver and patient. This study may help registered nurses understand the needs of the patient recovering from AN and help them meet these needs in a better way.

SAMMANFATTNING

Titel:	Anorexia Nervosa: Vad gör att patienter mår bättre under sjukdomen och tillfrisknandet?
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Handledare:	Widell Johansson, Agneta
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Avsikt: För sjuksköterskor är det svårt att utveckla en bra sjuksköterske-patient relation när de vårdar patienter med anorexia nervosa (AN), eftersom det finns brister i deras förståelse för sjukdomen. För att kunna stärka relationen mellan sjuksköterskor och patienter är det viktigt för sjuksköterskan att förstå det lidandet som patienter med AN upplever och vad som kan lindra det. Syftet med denna studie är att utforska vad som får patienter med AN att må bättre under sjukdomens lopp och tillfrisknandet.

Metod: En kvalitativ metod valdes för att utföra studien. Sex självbiografier valdes som data till studien. Böcker skrivna på svenska och engelska användes. En kvalitativ dataanalys, enligt Dahlberg, användes för att tolka data.

Resultat: Resultatet presenteras i sju teman: att bli sedd som en individ bakom sjukdomen, att kunna känna tillit och hitta trygghet, att ta eget ansvar för tillfrisknandet, att hitta motivation för att fortsätta kämpa mot tillfrisknandet, att ens lidande uppmärksammas, att fylla ett tomrum efter sjukdomen och att stärka relationen mellan vårdare och patient. Denna studie kan hjälpa allmänna sjuksköterskor att förstå de behov patienter med AN har och hjälpa dem att bemöta deras behov på ett bra sätt.

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INTRODUCTION

Eating disorders are most common among young women in the Western world, and these past years the knowledge about eating disorders has increased. We know that recovery is hard and may take several years. We also know that while intense treatment can be helpful in the beginning relapses are common. The area that we know little about is how the patients view the process of recovery. The registered nurse should have knowledge of how the patients experience the encounters with the health care personnel and what they think of the care that they receive. The suffering the patients go through and how one can understand and relieve that suffering play an central part in the care that the patients receive. In order to be able to give the patients with AN high quality care, it is crucial for the general nurse to understand the suffering that the patient experiences and the factors that make the patient feel better.

Anorexia Nervosa (AN)

Anorexia nervosa (AN) is an illness that affects the patient physically and mentally. The illness is associated with a significant weight loss. Patients with AN perceive themselves as overweight and feel a constant fear of gaining weight (Bulik, Reba, Siega-Riz & Reichborn-Kjennerud, 2005). Personalities of those with AN may often be characterized by perfectionism, obsessive-compulsive thoughts, anxiety and a low self-esteem (Bulik et al., 2005; Serpell, Hirani, Willoughby, Neiderman & Lask, 2006). American Psychiatric Association (1995) has published DSM – IV which is used internationally and includes the diagnostic criteria for AN. The criteria for the diagnosis AN are that the patient refuses to keep the normal minimal weight for the age and height of the individual, or that the weight is less than 85% of the expected normal weight. The patient has an overriding fear of gaining weight, even though he/she is underweight, and has a skewed view of his/her own body image. The patients that have started menstruations, have missed three or more consecutive menstruations (a a).

According to Socialstyrelsens Folkhälsorapport (2005) dieting has increased greatly among Swedish adolescents. Some of these adolescents may become trapped in the dieting and develop AN. One Swedish study shows that 22 females per 10 000 and 1 male per 10 000 have been cared for in Sweden due to AN between 1990 – 1998 (a a). AN often debuts in adolescence between the ages of 13 and 16. However some are diagnosed with AN in their twenties or thirties, and recent studies show that children as young as 5 years old have high weight concerns (Andrist, 2003).

The images of very thin models and celebrities are shown by the media every day. These celebrities are role models to many adolescents, and young adults. Some of these adolescents may feel dissatisfied with their bodies, and therefore, feel pressured because they want to look like the celebrities, so they start dieting (Andrist, 2003). Some adolescents then find support to continue dieting on the internet. There are many websites that support anorexia. These websites provide the individual with information and tips on how to lose even more weight. They also give support to individuals with eating disorders,

and encourage them to continue their behavior (Norris, Boydell, Pinhas, Katzman, 2006; Harshbarger, Ahlers-Schmidt, Mayans, L., Mayans, D., & Hawkins, 2009).

The Importance of the Caring Relationship

According to Eriksson (2000) the most important aspect of the caring process is the relationship between the patient and the care giver (registered nurse). The relationship between the registered nurse and the patient is a meaningful part of nursing since one grows as a person during interactions with other people. This relationship gives the patient the opportunities to express his/her wants, needs, and problems to the nurse (a a). Reciprocity, trust and respect are fundamental in the relationship between the nurse and the patient. A starting foundation for such a relationship can be formed if the patient experiences a pleasant encounter with the registered nurse (Wiklund, 2003). The nurse-patient relationship can become a 'caring relationship' when it supports and encourages the patient's health processes, and has continuity. By continuity, Eriksson (2000) means that the patient's health processes can, without disturbance, develop into optimal health. This caring relationship cannot be forced by the registered nurse; instead, the registered nurse offers a possibility of such a relationship and waits for the patient's response. A well developed relationship between patient and registered nurse can both give power and relieve suffering (Wiklund, 2003).

In one study, Eriksson (1997) argues that the caring world is seen from the three different perspectives of the patient, the nurse, and the relative. The dominating theme from the patients' perspective was suffering; the suffering included losing one's dignity, not being understood, and being reduced to a mere illness. The one way to alleviate the suffering that the patients in the study felt, was for the nurse to understand the suffering that the patient was going through, and form a 'communion' with the patient (a a).

The Patients' Perspective on AN

Some anorexic patients see a psychological meaning in AN (Nordbö, Espeset, Gulliksen, Skårderud & Holte, 2006). For these patients, AN may be a way to structure and plan their daily life. By making up a set of rules, that they have to follow every day, they acquire stability, and security. Otherwise, they would feel disorganized, and the fear of gaining weight would intensify. According to Nordbö, et al. (2006) patients can avoid negative feelings, and experiences through AN. They create a different personality, and feel better about themselves. These patients also express that they receive more care, and concern from their loved ones than they did before they were sick, and therefore, they feel less vulnerable. Other patients might use AN as a way to inform people around them that they are experiencing difficulties (a a). At the same time, there is proof that patients with AN might have a wish to recover (Nordbö, Gulliksen, Espeset, Skårderud, Geller & Holte, 2008). However, their motivation could be affected by the different feelings that they feel. According Nordbö et al. (2008), joy and spontaneity fill an individual with happiness, and eagerness. This makes an individual feel good about oneself. The higher self-esteem increases the patients' motivation to recover. The patients' wishes to recover increase when they feel strength, and self determination, along with feelings of acceptance towards oneself. However, the patients with AN seem to be most motivated to recover due to the

fear of losing their plans for the future and the loss of social life due to AN (Nordbö, Gulliksen, Espeset, Skårderud, Geller & Holte, 2008).

Caring for Patients with AN

Registered nurses may feel that it is a big challenge to care for patients with AN (King & Turner, 2000). Due to the fact that most nurses working in hospitals do not have a higher education in psychiatry, they have a hard time understanding the recovery process of AN, and what the patients go through (Ramjan, 2004). Some nurses may get frustrated because they believe that the patients cause their own illness, and starve themselves. This frustration could cause the nurses to be skeptical, and pessimistic towards the patients' recovery (a a).

It can be difficult to develop a caring nurse–patient relationship due to a circle of mistrust between the nurses and the patients. In caring for patients with AN, there is risk that the patients might fight against the nurses because the patients do not want to gain weight; they try to avoid it in every possible way. The patients might not trust the nurses that care for them just as much as the nurses might not trust the patients because they think that the patients are deceitful (King & Turner, 2000; Ramjan, 2004). Caring for patients with AN under longer periods of time seems to affect some registered nurses in a negative way. This due to the fact that their values of trust, non-judgment and equal care for all patients are questioned (King & Turner, 2000).

Parents' Experiences

Some studies show that few parents seem to understand the complexity of AN, and that many parents place the blame on themselves for their child's situation (Whitney, Murray, Gavan, Todd, Whitaker & Treasure, 2005; McMaster, Beale, Hillege & Nagy, 2004). The parents from one study wished to control the illness, and felt helpless since they could not. They were affected by the illness socially and mentally, and were frustrated due to the lack of understanding from others, especially health care professionals (Whitney, et al, 2005). Another study shows that the carers put in a lot of time, and energy to find help for their loved ones. The parents experienced the interactions with health care professionals negatively; they felt excluded, and not involved in their child's care due to the health care professionals' attitudes, and stereotypes of patients with AN (McMaster, et al, 2004).

The Research Issues

AN has become a common psychological illness among adolescents (especially females) in our society. The number of pre-teen children developing AN has increased under the recent years. Research shows that registered nurses have difficulties developing a caring relationship with AN patients, due to the lack of trust for the patient, and the lack of understanding of the illness. It is important for the nurse to understand the suffering that the AN patients experience, and what makes them feel better, to be able to improve the patient-nurse relationship. Being aware of the patients' feelings and values could increase the mutual understanding, and improve the care of the patients with AN.

AIM

The aim of this study is to explore what makes patients with AN feel better during the illness and the process of recovery.

How can the patients' suffering be understood?
Are there ways to relieve the patients' suffering?

METHOD

Qualitative method

A qualitative scientific approach was used to conduct this study. Qualitative research focuses often on discovery, description, and understanding of the phenomenon that is being studied. The researchers often believe in multiple realities, and value subjectivity. In qualitative methods, the researcher has a commitment to the participant's viewpoint, and must limit the disruption of the phenomena that is being studied, as much as possible. The results are usually presented with a literary style and include numerous informant commentaries (Streubert & Carpenter, 1999).

The aim of narrative research is to understand human communication and language in a variety of contexts (Lyckhage, 2006). The narratives used in research do not have to be created exclusively for an actual study. Autobiographies may also be used. Autobiographies are stories of one's life. From a nursing-science perspective, they are stories that describe how an individual experiences health, suffering and nursing care. Even if autobiographies are written with the purpose to inform or to entertain, they often contain experiences described with such generous detail that they can be used in research (Dahlberg, 1997).

Data Selection

The search for data was conducted using two databases: to find Swedish autobiographies the LIBRIS database was used, and to find English autobiographies Google-Beta book search was used. In LIBRIS the words 'anorexia' and 'biografi' generated 17 matches. In the Google-Beta book search database the word 'anorexia' in the title, and 'autobiography' in the search field was used. The language was chosen to be English and the publishing year between 2004 and 2008. This generated 59 matches. The summaries of all the 76 books were read, and the autobiographies to be included in the study were selected as following.

The autobiographies that are included in the study have been written by both males and females, regardless of their age during the time they suffered from AN. However, only autobiographies that fit the following three criteria were considered for the study. First, that the information in the autobiographies matches the aim of the study. Secondly, that the authors of the autobiographies have received some sort of professional help for their illness, whether it was hospitalization or admittance to an Anorexia day clinic. Lastly, that the autobiographies were published between 2004 and 2008. Using these criteria, the following autobiographies were chosen:

Arnold, C. (2004). *Running on Empty: A Diary of Anorexia and Recovery*. (USA) (184 pages).

Grahl, G. A., (2007). *Skinny Boy. A Young Man's Battle and Triumph over Anorexia*. (USA) (240 pages).

Kingsley J., & Kingsley A. (2005). *Alice in the Looking Glass*. (United Kingdom) (200 pages).

Mattsson, J., Gansmoe, J. (2006). *Svältland: (Landet bortom allt förnuft: en dagbok om anorexi)* (Sweden) (45 pages).

Åkerman, S. (2004). *Zebra flickan*. (Sweden) (271 pages).

Österberg, H. (2007). *Varje dag har vi en liten tävling*. (Sweden) (194 pages).

Summary of the Autobiographies

The author has chosen to include a short description of the six autobiographies being used in this study. The summaries are meant to help the reader get a better understanding for the authors of the autobiographies, in addition to the themes and quotes that are to come in the results of the study.

Running on Empty: A Diary of Anorexia and Recovery

Carrie Arnold describes that her anorexic thoughts began when she was in middle school, but she did not get sick in AN until she was in her third year of college. She writes about the struggles she had to face while she was at an anorexia recovery clinic and the struggles that waited for her after she left the clinic.

Skinny Boy

Gary A. Grahl started starving himself and compulsively exercising when he was in high school. He has been hospitalized for AN multiple times and describes how he managed to accept his illness and himself, and in the end recover, with the help of health care personnel and family.

Alice in the Looking Glass

This is an experience told from both the mother's and the daughter's point of view. In this study, however, the main focus was on Alice's account of her experiences. When she was only 11 years old she was diagnosed with obsessive-compulsive disorder (OCD). AN came when she was 13. She describes how she fought against everyone, even the people she loved the most, to be able to retain the anorexia that gave her control. Until, she realized that she could no longer live so alone, and had to join the fight to recover.

Svältland: landet bortom allt förnuft. En dagbok om anorexi

This diary was written by Johanna Mattson and her mother Jeanette Gansmoe. Johanna is 22 years old when she falls ill in AN. She describes her life in the lonely "Land of Starvation" and how she, with the help of her mother, is able to leave it behind.

Zebra flickan

Sofia is 18 when she writes her experiences of AN and self-destructive behavior, which started under childhood. She has been in and out of hospitals under her childhood and teenage years and describes how miserable and misunderstood she had felt there. With the love and acceptance of her family, her therapist and a group of girls from theater class, she could overpower her self-hate and strive for a brighter future.

Varje dag har vi en liten tävling

This is a diary written between 1999 and 2004. Hanna Österberg started writing it when she was 19. She was attending University, had a long-term boyfriend and a large group of friends. Still, Hanna cannot help but let Anorexia take more and more place in her life. Hanna goes through a few AN treatment day clinics throughout her recovery and finally decides to find something more meaningful than the illness to fill her life with.

Data Analysis

The author has used a qualitative method of data analysis as described by Dahlberg (1997) to study the autobiographies. During this analysis, the phenomenon that is being studied should be interpreted through a nursing perspective. This method of data analysis involves three phases: understanding the data as a whole, then analyzing it and breaking it down into parts, and lastly putting those parts together into a new whole. The entire process of the analysis must be done with openness. This means not allowing certain theories, categories or one's own assumptions direct the analysis in a certain pre-defined direction (a).

The first step of this data analysis method involves seeing the material, in each autobiography, as a whole. Therefore, it is important to read each autobiography unabridged so that an overall understanding is obtained. This entirety is then the connection for significant parts of the text that develop during the actual analysis, which is the next step (Lyckhage, 2006). During the analysis, the significant parts of the texts are separated from their context. However each of these significant parts must be understood in relation to the meaning of text as a whole. When these significant parts are identified they must be marked in the text, and later grouped based on their likenesses and differences. From the themes and categories that arise, a pattern can be described. The last step of the analysis is putting the significant parts of the data together into a whole that describes the studied phenomenon in a new way. The patterns that arise during the analysis can be described in a summarizing text using, for example, themes (Dahlberg, 1997).

First, eight autobiographies were read, separately, in their entirety to get a general understanding of the texts. Two autobiographies were excluded, since they contributed very little to the aim of the study. The six autobiographies, that are included in the result, were then read a second time and the significant parts were marked in the books and then written out on the computer. The significant parts were reread and compared with one another two times until obvious patterns emerged. Based on the patterns that were found, the significant paragraphs and quotes were placed into one of the 9 preliminary themes: seeing the whole person, trust and security, finding motivation, accepting the illness, filling a void, suffering, taking responsibility, realistic expectations and showing concern. After these themes were studied more closely, it was found that some of them were directly related and therefore, were merged together. The outcome is the final 7 themes that are presented in the results. Lastly the definitive titles were given based on the contents of each theme.

ETHICAL CONSIDERATIONS

The essential ethical principles for research must be reviewed and taken into consideration before the study can be conducted. In qualitative research, it is important to apply the principles of beneficence and justice by providing anonymity and/or confidentiality to the research participants (Streubert & Carpenter, 1999). Since the authors of the autobiographies that are going to be used in this study voluntarily published their experiences of AN, anonymity is not possible. Therefore, the researcher must protect the authors' integrity by interpreting the collected data reliably and correctly, and be sure that the presented results are based on the views expressed by the authors (a a).

RESULTS

The themes that developed were based on the personal experiences of the authors under their recovery. The themes that were found are: being seen as a whole individual behind the illness, being able to trust and find security, taking responsibility for recovery, finding motivation to keep fighting towards recovery, when one's suffering is noticed, filling a void, and the strengthening of the relationship between care giver and patient. The substance of each theme is first presented, followed by one or more quotes that best exemplifies the theme. To get an overview of which autobiographies each theme is based on see Table 1. To make the text more legible, the author of this study has chosen to use letters, instead of the titles of the autobiographies or names of the authors, as a way of referencing to the books. The letter that corresponds to each autobiography is verified in table 1.

Table 1. Each theme in relation to the autobiographies.

Themes	Alice in the Looking Glass (A)	Svältland (B)	Skinny Boy (C)	Varje dag har vi en liten tävling (D)	Running on Empty (E)	Zebra-flickan (F)
Being seen as a whole individual behind the illness	X	X	X	X	X	X
Being able to find trust and security	X	X	X	X	X	X
Taking responsibility for recovery	X	X		X	X	X
Finding motivation to keep fighting towards recovery	X	X	X	X	X	X
When one's suffering is noticed		X		X	X	X
Filling a Void	X	X	X	X	X	X
Strengthening the relationship between care giver and patient	X	X	X	X	X	X

Being Seen as a Whole Individual behind the Illness

Seeing the actual person behind the illness, rather than an anorexic, was vital to strengthen the individual's well-being. Many of the authors of the autobiographies (from now on, authors) felt frustrated when people in their surroundings were not able to see them as a whole individual. Some felt that other people judged them by the way that they look, thinking that food is all that the individuals worry about, not having much of a personality otherwise (A, B, D, E, F).

Ibland verkar det som om människor tror att jag är min sjukdom. Att jag helt tappat min personlighet och bara är en vandrande ätstörd. Jag vill skrika att jag finns kvar, lite dold kanske (Matsson, 2006, p. 17).

However, most of the authors described that it helped when others could see behind the illness, noticing the individual. The focus shifted from the illness to the patient, helping him/her relax and forget about anorexia, even if just for a few moments. The fact that others could see that there was something more to the individual than the illness, made the authors feel that as well (A, B, C, D, E, F). Here, one of the authors describes his relationship with a nurse from the unit where he was admitted:

My anorexia idiosyncrasies don't seem to faze her, and she treats me like her college roommate. I like the free-falling companionship. It's uncensored and spontaneous, and she's not the least bit interested in psychoanalyzing me. This is new for me (Grahl, 2007, p. 150).

When the authors felt that people around them saw them as they were behind AN, they could let their guard down and be themselves. It was significant that they could open up to people and still be accepted (A, B, C, D, E, F).

Jag som hade trott att jag skulle få sitta ensam. De behandlade mig som om jag var en av dem, som om jag varit med dem i all evighet... (Åkerman, 2004, p. 79).

Being Able to Trust and Find Security

Patients with AN had a hard time trusting others and have therefore held back, too afraid to open up and share their feelings. Once they came into contact with people they got along well with, and the trust between them began to grow, the patients felt it was easier to share their feelings and found relief. Trust developed both towards other patients, staff members, family members and friends. However, it was important that the trust was mutual (A, C, D, E, F). One author mentions how in the units that she was admitted to she could not trust any of the workers because they were not willing to share anything about themselves with her. She then found that her psychotherapist (Mia) was much easier to trust because she also trusted the her:

Jag visste nästan ingenting om skötarna, medan de visste allt om mig, från hur många gånger jag hade sett "Kristina från Duvemåla" till när jag hade haft min senaste mens. Om Mia fick jag veta allt jag ville. Undrade jag något så svarade hon... (Åkerman, 2004, p. 30).

Many of the authors longed for a sense of security; to be able to let go of all the nasty thoughts and feelings that they had and find something that made them feel safe. Some of

the authors found this security in a special place where they could feel at peace and be themselves; others, in a person that they felt comfortable with. However, some wished that they could, under the course of the illness, let go of all responsibility and be taken care of by others (A, B, C, F).

Jag har många gånger under sjukdomens lopp önskat att jag vore bebis igen. Att bara överlämna mig åt någon annan, att slippa ta beslut, att slippa negativa tankar och vara nervös för allt. Att slippa ha ångest. Att bara ligga varmt omlindat i mammas famn och inte ha några som helst krav på mig (Matsson, 2006, p. 11).

Taking Responsibility for Recovery

The first step to making a recovery from AN is being able to accept the illness. When the authors first realized that anorexia was a problem, only then could they accept the help that was offered to them from family members and caregivers (A, B, D, E, F).

...help doesn't quite register with you. It doesn't mean jackshit until you are ready to accept it (Arnold, 2004 p. 16).

All of the authors described a sort of inner battle in their minds between the “healthy brain” and the “sick brain”; meaning that they were struggling to decide whether they should let go of the illness and try to recuperate or if they should continue holding on to AN (B, D, E, F). Making this choice is what is meant by taking responsibility for recovery. In the following quote Hannah describes the questions that arose in her mind while trying to make her choice:

Hur ska jag göra? Ska jag gå bakåt och sluta äta det som jag nu lärt mig att äta? Ska jag gå ännu längre tillbaka än förut och se till att bli inlagd på sjukhuset? Ska jag stanna kvar på den nivå jag är på nu. Ska jag gå framåt (Österberg, 2007, p. 53).

Once the authors chose to get better, it was up to them, with the help of their families and caregivers, to improve their health. The help that the patient receives is very important, but the significant part is that the patient him/herself makes his/her own decisions and fights against AN (A, B, D, E, F).

Finding Motivation to Keep Fighting Towards Recovery

Motivation gives one courage and energy to continue to keep fighting towards recovery. There were various ways in which the authors could find motivation. They often found motivation when they had something positive to look forward to. This may be looking forward to school, meeting one's friends, moving to a new place or something as simple as a birthday party. Having something to look forward to, keeps the patient's thoughts on things that are positive rather than the depressing thoughts that the illness contains. It also makes the patient feel like one has a worthy existence and a place in the world (A, B, D, E, F). Sofia tells of the theater lessons that she attended and how the entire week that was all she looked forward to:

Jag var nästan alltid först på Teaterlådan, och var alltid sist ut. Veckorna var för mig bara en sju dagars lång väntan på tisdagskvällarna. Ingenting kunde få mig att avstå från att

komma dit. Teaterlektionerna gav en blick in i det liv jag ville leva. De gav mig vetskap om att det fanns möjlighet att vara lycklig (Åkerman, 2004, p. 167).

By having something positive to look forward to, the patients felt that there was hope and a possibility of living a happy life.

Another way the authors could find motivation was by feeling like they were understood and appreciated by others, and as a result less alone. This support came from both co-patients the authors have met and from the members of the staff. One aspect of this, that was significant, was being able to share their feelings with people that could understand and acknowledge those feelings. The authors experienced their thoughts as something extremely hideous and distressing. Therefore, it was meaningful to be able to let go of them for someone that could understand (A, B, C, D, E, F).

I found my talks with Sara (Alice's counselor) really helpful; she understood exactly what I was feeling and if I was ever struggling to find the right word to convey my thoughts, she knew exactly what I was looking for. From her experience in dealing with people with similar thoughts, I felt less alone (Kingsley, A. & Kingsley, J., 2005, p. 136).

Acquiring something positive increased the authors' motivation to keep fighting towards recovery as well. Acquiring something positive can mean receiving back one's rights for behaving well at the hospital, rebuilding one's relationships, regaining confidence as well as feeling happiness and hope (A, B, C, D).

...but absorbing every speck of warmth and unconditional love that emanated from the person next to me. I positively ate it up. The girl who wouldn't, couldn't eat anything, could still, at the very least take in love and hope (Arnold, 2004, p. 126).

The final factor that increased the authors' motivation was the fear of missing out on the future. Once they had started to recover, they saw a glimpse of everything that they had lost due to AN. They were afraid of losing more than they already had lost and of being completely alone with the illness. This fear motivated them and gave them courage to keep on fighting when the road to recovery became rocky (A, B, E, F).

Ibland bar det emot att fortsätta mot det friska. Det innebar ju att jag skulle komma längre bort från det som fanns åt andra hållet. Men gick jag tillbaka skulle jag förlora Teaterlådan, Fredrik, friheten och framtiden. Jag ville vara någonstans där jag visste vem jag var (Åkerman, 2004, p. 264).

When One's Suffering is Noticed

Many of the authors mentioned that not being listened to or understood by health care personnel and family members brought them anguish. One big hurdle all of the authors faced in their encounters with health care professionals was not being seen. The writers longed to be seen as patients with a substantial illness that required the same amount of care and attention as patients with physical illnesses received. Some of the authors did not think that they had a real illness. The fact that AN is not a real illness was confirmed, in their minds, when the health care professionals did not show them the same amount of concern and care as for patients with different illnesses. As a result, the writers had a wish

to have some sort of physical illness, so that their pain would be visible to outsiders (B, D, E, F).

Jag skämades, för jag önskade verkligen att jag haft en sjukdom som syntes utanpå, en som alla kunde se och förstå hur ont den gjorde. Det kändes groteskt och förbjudet att önska en sådan sak, men vanliga människor förstod att en person med ett stort operationsår kunde ha fruktansvärt ont. De kunde däremot inte begripa att en ung tjej, som såg så glad ut, kunde ha så ont i själen att hon kräktes i sängen för att ångesten gjorde så ont (Åkerman, 2004, p. 23).

The writers also felt like they were often not taken seriously by the health care professionals they encountered. This was particularly difficult for them to handle. They gathered all of their energy to be able to discuss their eating problems and emotional issues only to be ignored or disregarded. Here, Hanna explains how after she finally gets the strength to call an anorexia team for help, they answer that they have to take her case up at a conference to see if she can be admitted, and hang up the phone:

-Ja, nästa onsdag kan vi ta upp dig på vår konferens och se om du passar vår behandlingsmodell.

Det är allt jag får fram. Jag vet inte vad jag ska säga. Efteråt känner jag mig ledsen. (...)Jag trodde att det var tvärtom. Borde inte behandlingen läggas upp efter patientens behov?(Österberg, 2007, p. 16).

After such encounters with people that the writers expected would help them, they began to give up hope and lose faith in the health care system (B, D, E, F).

The writers experienced that the health care personnel did not always understand them nor recognize their thoughts. Just because AN patients are gaining weight and their physical state is stabilized does not necessarily mean that they are recovering from the illness. The fact that many health care professionals thought this to be true caused the writers great frustration. The ones who cared for the patients did not seem to have an understanding for how weight gain actually affects patients with AN, emotionally. These experiences of being misunderstood made the writers feel insecure and disappointed and a need for them to prove that they were still unwell resurfaced (B, D, F).

Alla hade tyckt att jag såg så frisk ut när jag hade höfter, bröst och runda kinder. Men jag blev rädd när de sa så. Jag var inte frisk än, jag fick inte se frisk ut förrän jag kände mig frisk inuti också (Åkerman, 2004, p. 42).

Filling a Void

The writers had all lived for Anorexia under their illness, and trying to imagine themselves without it, was devastating. It was like losing a piece of oneself. The writers had seen and defined themselves as ‘anorexics’ for such a long time that they felt as if they would be nothing without Anorexia. The illness had been such a big part of life that there was a huge void that needed to be filled once AN was let go of. Once the writers began to recover and let go of Anorexia, they struggled to find something worthy to fill the emptiness the illness left behind with (B, C, D, E, F).

Vem är jag egentligen utan svälten? Finns det kvar något? Det är klart att det måste bli ett tomrum. Jag har levt för svälten, varit vän med den, delat glädje och sorg med den. Känt mig trygg i den och kunnat vila i den. Vad ska jag fylla det tomrummet med? (Matsson, 2006, p. 16).

Filling this void left by AN gave the authors determination and control to keep on fighting towards recovery and was vital to keep them motivated. The empty space needed to be filled bit by bit with positive experiences not involving Anorexia, with interests and hobbies the authors could share with others. These experiences of wholeness gave the writers an inside look of what it is like to be 'healthy' and filled them with joy, energy, and the power to keep on fighting and to find a new identity free from AN (A, D, E, F).

Min nya identitet blev att jag hade varit sjuk men att jag slogs för att bli frisk. Folk förväntade sig att det skulle gå bra för mig, och det var upp till mig att bevisa att jag kunde (Åkerman, 2004, p. 237).

The Strengthening of the Relationship between Care Giver and Patient

It was evident that having a well developed and mutual relationship between the patients and health care personnel was meaningful and appreciated by both parties. It was visible when the care givers showed concern by performing tiny gestures of kindness and understanding. One of the writers appreciated when the doctor that she first met, for only one appointment, called months later and asked how she was doing. Another writer found comfort when one care giver read a story for her or held her when she was having anxiety attacks. Furthermore, it was indirect acts of kindness that showed the care givers' concern towards the patients; like being careful when examining the patients and respecting their integrity (A, B, C, D, E, F).

Jag hade trivts bra på vanliga sjukhus förut. Där var sjuksköterskorna inte känslokalla, även om jag fick en del onda blickar från dem som tyckte att jag kunde skärpa till mig. Men de allra flesta var snälla, och var så försiktiga med sina nålar och slangar (Åkerman, 2004, p. 208).

Another way to strengthen the relationship was to have realistic expectations of the patient in order for the individual to succeed. It was important for the authors that the tiniest bit of progress they made towards recovery was noticed by those surrounding them. Health care personnel could not expect too much from each patient or be too critical or judgmental. This only resulted in frustration and mistrust from the patients. The authors usually had very high expectations of themselves and often criticized and doubted their own abilities. Therefore, it was also essential that each individual had realistic expectations of oneself. This could be done with aid and support from health care professionals (A, B, E).

I've been told, many times, that I need to view myself and my abilities in a more realistic fashion. I am human. I am not flawless. I do not have to be. This new mantra of mine hums constantly in my brain (Arnold, 2004, p. 169).

Summary of the Results

The results show that in order to make the patient with AN feel better measures from both the patient and the care giver are required. That which the patient can do oneself is

accepting the illness, taking responsibility for recovery, finding motivation and trying to fill the void after anorexia with something positive. The care giver should see the person behind the illness, open up to the patient to try to establish trust, have realistic expectations of the patient, listen and try to understand the patient, accept the patient as he/she is and give him/her hope. All of these factors help to strengthen the relationship between the care giver and the patient, making both parties involved.

DISCUSSION

Discussion of the Method

A qualitative scientific approach was used to explore what makes patients with AN feel better under the illness and the process of recovery. Qualitative methods focus on discovering an individual's experiences and feelings of an encounter or an event. This offers data that portrays the studied phenomenon from the participants' point of view (Streubert & Carpenter, 1999). The advantage of using a qualitative method in this study is that the results can give an increased understanding of what makes patients with AN feel better, from a patient's perspective. One disadvantage of using a qualitative method, according to Olsson & Sörensen (2004), is that the results cannot be generalized, since the amount of participants is small; meaning it does not represent the entire AN patient population.

The data that is presented in the study was gathered from autobiographies. There are a few reasons why a researcher might prefer to use autobiographies in a study. A written narrative allows the informant to explain the information as thoroughly as he/she wishes. Using written narratives to collect data also gives a description of the informants' experiences without a dialog between the researcher and the informant. There is both an upside and a downside to this. The upside is that the informant is not affected by external influence; for example, an interviewer that can steer the conversation down a certain path. The downside, however, is that the informant does not have an opportunity to elaborate the information once the written narrative is in the hands of the researcher, leaving it up to the researcher to understand the content (Dahlberg, 1997). When using autobiographies one must also be aware that there is always a selection of the material that is included as well as the material that is left out (Lyckhage, 2006).

The method of data analysis that was used, as described by Dahlberg (1997), involved first understanding the data as a whole, then breaking it down into parts, and lastly putting those parts together into a new whole. This process seemed a natural way to analyze the autobiographies. In theory, this process must be done with openness; understanding the text as it is, without filtering it through one's own assumptions or theories. This openness is never complete; as a human one has always his/her preconceived opinions and theories and this can be an obstacle when analyzing data (a a). To minimize this risk as much as possible, the author of this study has deliberately held back her own beliefs and knowledge of the subject, as much as possible, so that her conceptions could not steer the process of analysis. Having a second party to discuss with and to verify the themes can also strengthen the validity of the analysis (Streubert & Carpenter, 1999). In this case, the study's author's tutor was used to carry out these discussions.

The autobiographies that are included in this study were written by authors of different genders and different age at the time of the illness. This makes the results more credible and gives a more multifaceted account of the phenomenon. The publishing year of the books was limited to include only the most recently published autobiographies. This strengthens the validity of the results as well. The fact that the autobiographies are from different countries could mean that the results of the study may also be conveyed in other

countries. However, having in mind that health care operates in diverse ways around the world; it is not viable to say that the results apply in other countries.

Discussion of the Results

Before beginning the discussion of the results, it is important to clarify that the discussion is written with the perspective of what a registered nurse can do to make the patient with AN feel better. The authors of the autobiographies describe the encounters with a variety of health care professionals in their stories. However, I believe that the results of this study depict the patients' experiences broadly and can be applied by registered nurses when caring for patients with AN.

The aim of this study was to explore what can make patients with AN feel better during the course of the illness and the process of recovery. Two questions that the author of this study attempts to answer are how the patients' suffering can be understood and if there are ways to relieve the patients' suffering. The results of the study show that the authors experienced suffering due to the illness, but also due to the care that they received. One source of their suffering came from the health care professionals when they did not see, understand, or take the patient seriously. In doing so the care giver violates the patient's dignity and reinforces the patient's feelings of mistrust towards the care giver. According to Ericsson (1994; 1997), the patient longs for empathy, compassion and an understanding for the suffering that is felt. As a care giver of a patient with AN one must try and put oneself in the patient's situation.

One simple way to try to understand the patient's suffering is to simply ask and listen to the patient's response, and most importantly, take the patient seriously. A study (Vanderlinden, Beuis, Pieters & Probst, 2007) shows that therapists and patients actually share a similar view about what is necessary for treatment to be successful, but that the therapist needs to have a good understanding of the patient's needs. To be able to learn from a patient and understand his/her experiences, one is only required to ask about the patient's opinion and listen carefully to his/her reply. Lamoureux & Bottorff (2005) mean that progress in recovery could be made only when the individual encountered someone they could trust and rely on. The results of the current study show that trust and security are vital in order for the patient to start discussing their thoughts and feelings with the health care personnel. Trust must be reciprocated, and in order to gain the trust of a patient the registered nurse must trust and dare to be open towards the patient as well.

The results also explain how a registered nurse may be able to relieve the patient's suffering by making him/her feel better. Being seen as a whole individual shifted the focus from anorexia to the patient as he/she was without the illness. When caring for a patient with AN, the registered nurse must not concentrate on the illness but on the patient as a whole. This is verified by Eriksson (2000) who believes that the care giver must meet all of the aspects of a person (patient), even if the illness is concentrated to only one part of that person. Another part of this is the understanding what the patient goes through during recovery. For example a patient's weight gain is not a direct implication that the patient is feeling better on the inside. On the contrary, in this study, the stabilization of the patients' physical state scared them, since it meant that they did not look sick, but they still felt unwell on the inside. This is hard for many registered nurses to notice and understand since there is very little psychiatry that is included in the education program for general nurses.

Past research (Ramjan, 2004; King & Turner, 2000) highlights the fact that it is necessary for nurses, working with this patient group, to have an education in psychiatry, to be able to understand what recovery entails for the patients, which most general nurses do not have.

Another factor that may also relieve the patient's suffering is helping the patient to find motivation for recovery. This may be done by emphasizing the positive things that the patient has in his/her life and help him/her find new things he/she views positively. The fact that motivation is a big part of the recovery process is demonstrated in recent research (Nordbö et al., 2008; Vanderlinden et al., 2007). The patients in one study (Nordbö et al., 2008) could find motivation in feeling joy and strength, having self determination, accepting oneself and fear of losing future plans; these results correspond to what was found, in terms of motivation, in the present study.

By strengthening the nurse-patient relationship, the registered nurse may make a patient with AN feel better as well. Past research shows that registered nurses feel that caring for patient with AN is a challenge since developing a caring nurse-patient relationship is difficult (King & Turner, 2000; Ramjan, 2004). While more recent research shows that a good relationship gives the patients support which is necessary for recovery (Vanderlinden et al., 2007; Lamoureux & Blottorff, 2005). The nursing process comes down to a series of tasks if the process is not based on a relationship between the patient and the nurse (Eriksson, 2000). The results of the present study mean that the nurse-patient relationship can be strengthened by showing the patient concern, listening to the patient and taking him/her seriously, and having realistic expectations of the patient. Tiny gestures of kindness and understanding made the patients feel accepted and appreciated.

Only by first accepting AN and realizing that they want to get better for themselves can the patients gain from the help that is being offered to them. This study, as well as recent research (Lamoureux & Bottorff, 2005; Fredrici & Kaplan, 2008; Vanderlinden et al., 2007; Keski-Rahkonen & Tozzi, 2005), shows that it is often difficult for the patients to let go of anorexia since they fear that they have no identity without it. For care givers it is important to accept and confirm the identity of the individual behind anorexia. By verifying that the patient has a personality behind the illness gives feelings of acceptance, and motivation he/she may be looking for. In the care of patients with AN it is most important to have a holistic view. Though it is essential for the patient to put on weight, one cannot just ease the physical symptoms of the illness and believe that the patient is better. The underlying problems, such as the insecurity and vulnerability that the individual is feeling, are just as important to care for. The issues causing AN lie deeply enrooted in the individual and must be seen and often require psychological help.

Conclusion

This study gives insight of what can make patients with AN feel better during the illness and under the process of recovery. The findings show that for recovery the patients must have a great amount of inner strength and be ready to give up the illness, while also using the resources provided for them by trusted health care personnel and family. There is still a lot to be learned about the illness from the patient's perspective. The needs of each individual patient differ and so should the treatment. Further qualitative research about the

patients' perspective of the process of recovery could contribute to further understanding of the patients' experiences and to the forming of individual treatment programs.

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