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Treatments for Eating Disorders: The Patients’ Views

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Eating disorders (EDs) have generated increasing concern in the last decades, both in the mental health field and in the general public. They are amongst the most frequent chronic health problems in adolescents, and the mortality rate of Anorexia Nervosa (AN) is one of the highest of all psychiatric illnesses. Clinical experience has demonstrated that EDs tend to be highly resistant to different modalities of treatment, and outcomes tend to be relatively poor, especially for those who do not receive early specialized interventions (Treasure et al, 2005). One study showed that of a sample of patients with AN who received inpatient treatment, less than 30% showed a good outcome and almost 60% had a poor outcome (Salbach-Andrae et al, 2009). Moreover, adherence is often poor, resulting in patients abandoning treatment; it is not infrequent for them to enter into treatment programs numerous times, both inpatient and outpatient, only to abandon them again. This not only worsens their prognosis but also implies a significant loss of resources for Health Services.

In this context, the fact that relatively little is known about patients’ subjective opinions about the treatments they receive becomes highly relevant: what aspects do they value the most? Which are the elements they value least and could contribute to them abandoning treatment? Which health services do they feel can best respond to their needs? Although EDs have been studied from different perspectives, this particular area has been neglected within ED research (Bell, 2003; Vanderlinden et al, 2007).

Another important aspect to consider is the frustration the treatment team experiences when patients abandon treatment despite the severity of their illness and the efforts that have been made to motivate them to adhere. However, previous research suggests that there are significant differences between aspects of treatment valued by providers and patients (de la Rie et al, 2008), and learning about the sufferer’s perspective could contribute to developing interventions which may be more effective.

The aim of this study was to identify the views of Chilean patients who have received treatment for an ED about these treatments, including aspects they value and feel have helped them in their recovery as well as aspects they feel have hindered their recovery or
been missing from their treatments. We felt it would be interesting to explore ED patients’ views in Chile since, to our knowledge, no previous study on this topic has been undertaken in a South American country.

2. Method

This was a qualitative, exploratory study based on the principles of the Grounded Theory Model developed by Glaser and Strauss (1967). This methodology is especially appropriate to access subjective processes from the involved individual’s perspective.

2.1 Inclusion criteria, recruitment and participants

Patients of the Salvador Hospital of Santiago, Chile (main public hospital for the Eastern Metropolitan Health Service of Chile) were contacted through key informants and invited to participate in the study. Inclusion criteria included having been diagnosed with an ED and having received or currently being in treatment for this condition in the Salvador Hospital. All patients who were contacted agreed to participate. The sample size was 10 patients. All participants were female, and their ages ranged from 16 to 47 years, with a mean age of 30.7 years. 6 of the participants had been diagnosed with Bulimia Nervosa, 3 with Anorexia Nervosa and 1 with Eating Disorder Not Otherwise Specified. All patients were currently receiving treatment for their condition.

2.2 Data collection and analysis

Semi-structured individual interviews were undertaken. Data were analyzed using open coding. After preliminary results had been obtained a focus group was held in order to corroborate the findings with the participants.

2.3 Ethical considerations

The study was approved by the Eastern Metropolitan Health Service’s Ethics Committee. All participants signed an informed consent document.

3. Results

The participants’ views generated four main themes, each one including positive aspects which patients felt had helped them in their recovery as well as negative aspects which they felt had hindered their recovery or elements which had been missing from their treatments. Each of these is described below and quotes are provided which illustrate these findings in the patients’ own words. Findings are summarized in table 1.

3.1 Personal and professional characteristics of care providers

The first theme involved personal and professional characteristics of care providers. In terms of personal qualities, participants valued health professionals who were empathetic, concerned, understanding, good listeners, and who they felt they could build a trusting relationship with:
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Table 1. Results
“The psychiatrist who is with me, ehh…we start to talk, and the first thing she says: I bet you don’t get any sleep, with two babies, and I understand you, because I have twins, so it’s like she empathizes right away, she, she inspires trust…so, those things, when one is sick and when one lacks things, are very important…all the other doctors, they have all been like…eh…particularly special with, with me, I’ve felt it like that…and that’s the very thing that motivates me to want to keep coming. I don’t know if it’s a, what’s it called, a characteristic of the people sick of bulimia and of anorexia, the lack of affection, the loneliness, and all that… the people who are going to dedicate themselves to this, give it importance, because one ehh, needs not the attention, but the understanding, because one doesn’t accept oneself, and someone has to accept you so they can help you to, to learn” (Interview 5).

“…I notice 100% of concern for me [from the psychologist]. Because, in fact, when at times I missed [the appointment], he called me, what’s wrong, and all that. So that is helpful, especially, for example, there were times when I didn’t feel like going out, and…I didn’t get up all day….so he understood me in that sense, he understood the fact that I missed once, because we reached the compromise that I wouldn’t miss… more than three times...” (Interview 7).

“I cared a lot about my psychologist, for the reason that we were more, more than psychologist and patient, we were like friends, so I trusted him a lot, it was like really fun, I liked coming, and yes, I felt like closer to him, not just like a doctor who tells you OK: this, and this, but I felt more, more closeness” (Interview 8).

“…”All three listen to me. My psychologist…has helped me a lot with my, with relationships with my family, everything. The psychiatrist also, has learned to listen to me quite a bit...” (Interview 7).

Regarding professional qualities of treatment providers which patients’ felt had helped them in their recovery, they identified being treated by a multidisciplinary team conformed by psychiatrist, psychologist and nutritionist, who worked together, as positive:

“What I most value, am grateful for, is having an entire team because if not…because I alone, I know I can’t come out of this alone, I’ve tried and, and that’s what I most find value in…I thank that I have an entire, that I have an entire team” (Interview 8).

“I’d never been in treatment before. And since one always heard that, I don’t know, anorexia and bulimia didn’t… in the public sector there wasn’t much…much solution, I mean… but actually, from January until today I’ve realized that it’s a, it’s a multidisciplinary team, that that’s why they sent me here…..yeah, because actually…everything goes like together with everything, I mean… everything is related” (Interview 3).

“…constant psychological and psychiatric support are needed…. and well, and nutritionist, it’s like a team more than anything, made up by a nutritionist, psychologist, psychiatrist” (interview 2).

“…there was a time when I passed out, I had, I fasted for two weeks, two whole weeks, I mean, and they wanted to hospitalize me and everything, and everyone knew, psychiatrist, psychologist, everyone knew. So I liked that, that they were all connected” (Interview 8).

Participants also described certain negative aspects of care providers which they perceived as obstacles to their therapeutic process. On a personal level, they described feeling a lack of dedication and commitment from some professionals, and feeling distanced from them which made it more difficult to establish trusting relationships:
“I’m actually not happy with the doctor’s care, not at all, I feel that… [he was lacking] dedication, because I feel that they are not very concerned… more than anything I think… I think what’s missing, lets say, being more dedicated, eh, getting more involved, if I commit, lets say with the treatment, that it be mutual” (Interview 4).

“I don’t know, it’s that I’ve always had the impression that psychiatrists make you feel that they know much more than what they know, you know? I feel that they are like square-minded people, that they don’t look beyond what they want to see. I don’t know, I see them like people that like, people that like feel superior quote unquote, like they know everything. So I never, for that reason I don’t, I don’t believe them much sometimes” (Interview 1).

“…one of the things I feel… is the distance from the psychiatrist” (Interview 7).

Participants also referred to receiving negative messages from some members of staff and how this stood in the way of their recovery:

“Ehh... well, constantly repeating that your weight is not healthy, that, that the bulimic attacks...or, for example, if I’m eating, eat everything, or because if not, after, don’t go throw it away. Messages like that... the nurses...it was that many would comment: there goes XX to vomit her food... and I was just going to the bathroom. So being constantly, like they have you marked, like if she goes to the bathroom she’s going to eliminate the food... it was like they were constantly repeating that, that you’re not well, that you’re sick, so they didn’t... they didn’t give like any solution... it was like they were constantly emphasizing that you were sick, and that everything you did was to sabotage the treatment. That was, that was more than anything what bothers or what obstructs [the treatment]” (Interview 2).

On a professional level, one cause for concern for participants was the lack of coordination and communication amongst the different professionals treating them, which meant they often had to tell the same things twice and which ultimately led them to lose their trust in the treatment team:

“I think that sometimes they don’t even read what the psychologist wrote...so, eh, I think that the two things don’t connect, they are like disconnected [...] they don’t form a team, because in fact when, eh, when two appointments came together, almost at the same time, the psychiatrist and psychologist on Monday, psychiatrist at eleven and psychologist at one, I was waiting for the psychiatrist for a long time...finally it was one, and I was still waiting for the psychiatrist, so in that moment...I told him, you know what, my psychologist is waiting for me, and he said: which is your psychologist?... he didn’t even know who my psychologist was, he didn’t even know him, I mean I had to like introduce them...so there I noticed that there was no connection [...] it’s like a waste of time... because I have to tell the same thing twice, and sometimes important details are lost, that a psychiatrist should know or a psychologist should tell him...so I sometimes need for these details not to get lost because...one can also make a mistake in the sense of giving medication...that’s what I think, that they should be more connected, more united, not so different” (Interview 7).

“The doctor who sees me now...told me: the exams came out really well...and suddenly I see an internal medicine doctor coming... and he started telling me that I had problems in this, and that, OK, and then I said: but how? If the doctor told me everything was fine. So I don’t understand it... so I thought that was strange, so if the doctor tells me it’s fine, and the other doctor started telling me other things, and on the side the nurse tells me the exams were bad, then I don’t know which of the three to believe, since the three are professionals...so, it made me
angry…I didn’t know who was telling me the truth…this is why I sometimes don’t believe much in doctors, in psychiatrists” (Interview 2).

Another thing which participants felt hindered their recoveries was that at times one of the professionals treating them had to leave and was replaced with someone new. This once again brought up trust issues for the patients, making them feel vulnerable, as if they were starting over or going backwards in their therapeutic process:

“What I feel that’s like negative is that I’m not going to see my psychologist any more because he’s a trainee psychologist and since he finished his training, I’m going to end up with another psychologist…it’s like starting over, because it’s really difficult for me to maintain trust with a psychologist, it’s hard for me… [I had] a psychologist with whom I could go happily to therapy because I’m going to talk with the person I like so much… so I think that the fact that I’m no longer going to see him is negative for my treatment, because I’m going to have to start over with another psychologist. […] It’s terrible because I had trust with my psychologist, which had been difficult to achieve…so, once again feeling like… vulnerable. Because one feels vulnerable in that sense… I feel vulnerable because… I have to tell the story again, I have to talk about the same things again, it’s like I already know it by heart…. It makes me feel… as I said, vulnerable, because it…it makes me sad, this makes me sad because, I mean, again! And, like going backwards, and going backwards makes me melancholic. And that, I feel, is negative” (Interview 7).

“I started off really well. I liked it, I had a good connection with the psychologist who, who saw me the first time, lets say, a good connection…the treatment was really good with her… she had to leave, and we started from scratch, the treatment gets totally lost… these changes like this, so sudden… from one psychologist to another, in the end for the patient… they don’t achieve anything, I mean, everything you achieved, gets lost, because actually...lost work, I find, starting over, the psychologist has to get to know you again. So it’s, it has been like going backwards, I find, the change. […] Don’t change the, the doctors, the psychologists, it’s starting over, it’s starting from scratch, going backwards, it’s delaying the...what had been accomplished, lets say, I feel that I got delayed. I got delayed” (Interview 4).

Participants also mentioned that having few appointments with their psychiatrists, sessions being too short and appointments being cancelled by their care providers had a negative impact on their treatments:

“…to start, the interviews are really short and…we have had, from the time I arrived, really few appointments [with the psychiatrist] because there was one time that I didn’t come, well that was my mistake, I gave notice and everything... after that every time I came, eh… which were like three, four months more or less, I had to be with the doctors who were on call, because, either he was sick, well, he could have been sick, no, I don’t know, but he was sick so many times in a raw that…it calls my attention, I think maybe he has lots of things to do… he could have been sick but not that long. I think that he had trips out of the country, then he came back, and those gaps, I feel it hasn’t, hasn’t been good” (Interview 4).

“My doctor, I think, is quite concerned about me, but they are not there all day [in inpatient ward], the paramedics take care of me more than the doctors…that’s the problem…” (Interview 6).

Finally, in terms of professional characteristics of care providers, participants identified that one central aspect which was missing from their treatments was for it to be undertaken by professionals who are specialized in EDs:
“I feel I need a professional who is specialized in what I have… […] maybe I’m not in the right treatment. That’s what’s going on. That’s why my father is now finding out about several centers which are specialized in eating disorders. So, he wants to find one that also convinces him. Because it turns out that no doctor can give him an explanation of why I am this way… […] but it’s so difficult because those specialized places, finally, are private. So, that’s the problem, that not all people have the financial situation to… change it, to change, I mean, to get a more adequate treatment” (Interview 1).

“And the lack of nutritionist, which I think is fundamental. I think there should be a nutritionist here, who was in charge, lets say, of the area of eating disorders” (Interview 4).

3.2 Types of interventions

A second theme which emerged from the participants’ responses involved the types of interventions they received during the therapeutic process, among which individual psychotherapy was highly valued. Patients’ described certain cognitive-behavioural techniques which they felt had helped them in their recovery, including having to fulfill certain tasks between sessions and working through a book with the help of their therapists:

“What I have found to be fundamental, at least with the psychologist that, that I started with….. I vented with her…what I couldn’t do on the outside, I did with her. She started making outlines, giving me tasks, lets say, [an] outline of my diet… every week I would bring her the outline. We would see each other every week, from one week to the next, with appointments… the amount that I ate, what I ate, what I thought of before I ate, eh, the purges, what I did to revert the purges, eh, any observation, lets say, that was important, the help I could receive, the people who know about the problem, if I had observed if my family worried about me. That was the task, lets say. I thought it was really good” (Interview 4).

“…my psychiatrist gave me a task with a book I was reading, some chapters I had to read, and work through them about how this is produced, I mean seeing, for example, that if there is a situation, from that situation there is a thought, and that from the thought there is a consequence from that, and that emotions are involved. So she explains through all those things and little by little I have come to understand all that is happening to me, which was that… I felt lost” (Interview 2).

“…methods…for example, writing down everything you eat, and realizing what is good for you and what is bad for you. So all these things help you… […] this book… the two psychologists who saw me here lent it to me…this little book ‘Risk and Prevention of Anorexia and Bulimia’… the first time they lent it to me was specific; read from this page to this page, and this one, this one and this one, and we’ll comment. The second time they lent it to me, they told me to read the whole thing. And then it captivated me because… I felt very identified…It speaks directly to you, to you as a patient. So, I think that, it makes you, makes you become aware that there are possibilities to get better” (Interview 5).

Patients also highlighted the importance of individual psychotherapy in helping them recognize and learn to deal with their emotions, and understand how their difficulties in the expression and regulation of their emotions related to their ED behaviours:

“…we have reached one of the important conclusions with the psychologist, that I suppress my emotions, the good ones and the bad ones, that’s why I don’t have a… positive concept of myself, because I don’t see anything, I don’t see anything good, and the bad I… I don’t know if I enlarge
it, but I do see it more clearly, so...that's what we are doing, learning to, to...feel, because one blocks oneself... in order to not have a bad time... one also prevents oneself from having a good time [...] I would like... [to] know the cause, why, why I'm like this...what happened before, although she tells me that actually many things have happened to me, which could be the cause of...but, above all, it's like a feeling of loneliness, on, on my part, from childhood” (Interview 5).

“... I would tell her I feel this and she [the psychologist] tried to find a solution as to why I felt that... she made me understand why I felt what I was feeling... I find that that helped me, because it, it made me... see the things in which I was wrong” (Interview 9).

“With him [the psychologist] we talk around forty-five minutes, and we talk about anxiety, specifically about anxiety...and how I feel, of...of why I feel that way...what I most think is how, how he has helped me to understand why I react in some ways... try to understand why I vomit, without there being a need to do so...it helped me a lot because no other psychologist or psychiatrist had made me understand why I was doing what I was doing, and in general he, eh, he was concerned with telling me why I was feeling that way, why I was so anxious, or why I vomited, because, eh, what it was that I felt before I vomited, and what it was that I felt after I vomited...he made me realize how I could stop this. Because I realized, OK, I’m very anxious, so I’m going to binge, to realize when I was going to binge, so, I’m going to binge, and stop in that moment. Say no. That like helped me...to listen to what was going on inside of me, why I did it, so, that for me, well, of all the things we talked about, I was very touched by some conversations that I had with him, so I left like meditating, and I meditated about this same thing every week, so, one of the things is to like realize that, for example, I vomited because...it was a way of like harming myself and not harming others, OK?, and several other things, and to try to stop this, that anxiety” (Interview 7).

Regarding therapeutic interventions which patients felt had not helped them in their recovery, treatments that focused solely on weight gain, without considering psychological or emotional aspects, were mentioned, and the importance of an integrated approach to treatment from the very beginning was highlighted:

“...in neither [hospitalization] a clear objective was achieved, I mean the only thing they achieved was making me gain weight, because for them...with your low nutritional condition, you can’t understand, you can’t reason many things, so having...the normal adequate weight, with that they could start treatment. But they focused so much on weight that I never had like psychological support, nor anything... that could like help me or [allow me] to understand why this happened, none whatsoever...they said: OK, you are here in the inpatient ward and here we feel you and everything, and when you leave...only then your treatment for the eating disorder will begin which would be as an outpatient. I found that sort of, like I don’t know, it didn’t make sense because it was like if one is in a process and all they did to me was make me eat, eat like they had ordered them to do....all I had on my mind all day was food, food, food, so no one helped me to like guide, how to avoid that...so that was, more than anything, the treatment that really didn’t work [...] because there’s something else there, I mean, it’s not just the issue of food” (Interview 2).

In addition, pharmacological treatments appeared to be less valued by participants, and in some cases family members, than psychological interventions:

“I find that the medication...for the binge episodes has helped me, but the antidepressants haven’t, I believe I have done it more on my own than with the medication, you understand? ... thanks to the psychologist I’ve been able to, lets say, eh, [advance] more than with the
antidepressant they give me, you understand? And that thing of... medication for everything, to
sleep at night... I've stopped taking those... I stopped taking them on my own, I found them
unnecessary and I've been able to sleep [...] I can't say everything has been bad... but I know
that also a large part of this has been due to the psychological support and because I've done it,
I've had the willpower, because on the other side I think that no, medication doesn't, doesn't do
everything” (Interview 4).

“He [my father] believes, tells me that the only thing they are doing is intoxicating me with pills.
On one hand he's right, because I take a lot of pills. I'm going to end up getting sick to my
stomach, I don't know, but they are a lot of pills. I think that of all those who are here, I think
that I am the one who takes the most pills” (Interview 1).

Another intervention which participants described as having a negative impact on their
recovery was absolute bed rest, which was perceived as a very restrictive measure:

“...one knows that what they are saying is really for your own good, but sometimes they like,
one tends to think that they exaggerate greatly, and it's like they take away your freedom, for example
I was here the first days in absolute bed rest. I mean, I couldn't move... so it's like, that all the
time, if I got up: XX, to bed! So it was like really bothersome, because I said, but come on, I don't
have that freedom that I want... being so locked up also anguished me...I also needed my
freedom to be able to do my things” (Interview 2).

“...I don't agree much with their, with the measures they take...for example having me in bed
without moving, or not walking, I find... I don't find it good for me” (Interview 1).

3.3 Support

Patients’ responses generated a third theme which had to do with the importance of feeling
supported throughout the road to recovery. Receiving constant support from their care
providers, feeling accompanied and contained by them was highly valued:

“The containment, the containment which they enable you to have, I mean, that I don't feel
alone. I don't feel like that I'm there, as yet another patient, like: lets feed her now and then she'll
leave. It's like that containment that they are constantly concerned about me, constantly
thinking about what's happening with me, I mean, even if they see me lying down too much,
with a certain face of some emotion... they ask me what's the matter, that... they are always
there...and that was what I felt I needed because before I felt like very alone, like very abandoned,
to put it in some way. So now I feel like that containment and constant concern, and I feel I
needed it” (Interview 2).

“Look, what I most highlight is, is like, the time, and the, I don't know if the interest, but...they
take good care of you, at least the Doctor [names her psychologist]...the whole thing has actually
felt quite nice. They have been like really fraternal... the nutritionist also, I mean I’ve felt like...
I don't know if love, but... like, like they support you a lot” (Interview 3).

On the other hand, participants mentioned the lack of support they felt during the night in
the in-patient ward as a negative aspect of their treatment:

“Here there are no nurses on call at night. If a patient becomes unwell at night a doctor has to
see her, or the paramedics. But here the paramedics are not awake all night, they go to bed and
sleep. So I say, what kind of...of what's it called...of rehabilitation centre is this?” (Interview 3).
Feeling supported and accompanied by their family members during the therapeutic process was also valued by participants. One patient portrayed how helpful it was for her to feel supported by her husband, and the positive impact it had on her recovery:

“...I would often get up to eat at night... I would get anxiety... and do something to myself at night. Many times, when I was doing well with my husband, he would pretend to be asleep and was paying attention to see if I did it or not at night, and one time I got up, I told him I wasn’t going to do it, I went and I did it, and he was paying attention, and he, he didn’t tell me straight away, he talked to me about it later on. So that helped me a great deal, it was like a click, and after that I went a long time without getting up at night, it was a way of containing me and, a help, I felt that it was a really good detail” (Interview 4).

However, later in the interview she described the feeling of loneliness that set in when she lost his support:

“I can’t [vent] with my close family, eh, in this case with my husband I had done it at some point and I had had his support, but I feel that now there hasn’t been much support, or he got bored, so, actually...he tells me that I follow him around, that I pursue him, and that... I’m sort of... obsessed with the problem, and in part I know he is somewhat right, but he also has to put himself in my shoes, I mean, what reasons there have been, and unfortunately, my life is based on this, it is bulimia... I think. I don’t know what would happen... if we weren’t together, maybe I could handle it better. I’ve thought about it. It’s been so many years, but... it’s like fear, actually, of ending up alone, something like that...” (Interview 4).

Finally, an aspect which patients mentioned as missing from their treatment was greater communication between their caretakers and the family members who constitute their stable support network:

“... I would have liked, for example, every once in a while, [for my psychologist] to talk to my family. I mean, to talk to me, and later a couple of weeks could go by and he could talk to my mother and tell her how I was advancing... the thing is that my father doesn’t really believe in this... my mother is the one who has been there with me always [...]. I would have liked for the psychologist to talk to my family... [about] the behaviours I’ve had, or the changes, or what I could improve...” (Interview 8).

3.4 Patient-centered care

The fourth theme that emerged from the participants’ interviews involved the desire for patient-centered care. Patients identified that in order to truly be at the centre of their own treatment they needed to be motivated, to feel that it was possible to get better, and to take responsibility for their recovery, and they valued receiving this motivation from their care providers:

“What treatments have I received with the nutritionist? Ehh, more than anything, it’s funny but it’s like, it’s more than anything a psychological treatment, because she says: you are, you are in charge of yourself now, you have to assume the responsibility for your recovery [...] when I arrived here, I arrived saying that I wanted to get better to save my children, to have them near me, to be well for them, but now I am starting to, to think, I’m still not convinced of this, but now I’m starting to think that it’s good for me, it’s good to do it for me. Not only for the children, [although] the children will also benefit, but it is something for me, and I think that is
very important because, with the little appreciation I have for myself, to start to do something for me… can change many things” (Interview 5).

“…if a patient with an eating disorder arrives to treatment like very unmotivated, I mean, that you can tell that [she has] zero interest in that, start motivating her little by little to a recovery… with positive messages, that she, that what she has is not, she’s not a sick person, rather she has a sickness that can be healed and that is not forever. Or, if it will be there… during her life… that she can control it, that she will be able to get to a point where she will be able to control it, and live her life, because this really, takes away your life” (Interview 2).

Participants described that once they were able to recognize their illness and become motivated to recover, they were able to leave the role of the “victim” and take a more active stance in their treatment, which they felt had positive repercussions for their recovery:

“Look, I was meditating about this, and what I most value is that they made me realize things I had not realized, I don’t know how to explain it, but it’s like, talking to me about the illness as it is, clearly, not as a victim… it’s like what helped me and I think I value a lot” (Interview 7).

“I think that more than anything I see how positive it has been to have recognized [the illness], because by recognizing the illness one can, one can help oneself, and one can be helped, while one doesn’t recognize it one can’t…it’s up to me, that’s very clear to me, it doesn’t depend on anybody else’s help, which they already gave me, and thank God it was positive, because I recognized [the illness], and I stopped dieting for a long time” (Interview 10).

Feeling like they were able to participate in their treatment plans was also valued by participants:

“… afterwards the doctor changed my medication, he told me that these were effective for the problem I have… but that I wasn’t going to gain as much weight as with the ones he gave me at the beginning. Because I told him that I wasn’t going to go any more because I was already gaining weight, I didn’t want to continue any more, so he made a whole change [in the treatment]” (Interview 10).

On the other hand, not being given all the information concerning their treatments was perceived as negative by participants, making them less willing to cooperate:

“… the paramedic comes and gives me another pill, which I though was like strange, I didn’t want to take it. Because first they have to ask me about things, or explain why they are giving me a pill” (Interview 1).

“[They should] explain a little bit the reasons for the restrictions” (Interview 3).

Finally, patients expressed that an individualized approach to care, which focuses on the specific needs of each person, was missing from their treatments:

“Me as, as a person, as ME, I would like to receive help for anorexia… I think that…that the patient has to be studied more and see which medication [is] effective that will really be good for the, the person, because we don’t all have the same body, we don’t all have the same mind” (Interview 9).

“We the patients are not all the same” (Focus group).

“They put us all in the same bag” (Interview 3).
4. Conclusion

The objective of this study was to explore the views of Chilean patients who have received treatment for an ED about these treatments, in order to identify the aspects that patients value and feel have helped them in their recovery as well as the aspects they feel have hindered their recovery. The participants’ responses centered around four main themes, which included positive and negative aspects of care.

The first theme involved personal and professional characteristics of care providers. On a personal level, participants valued care providers who were empathetic, understanding, concerned, and who they felt they could build a trusting relationship with, stating that this contributed to them liking their treatments and motivated them to “want to keep coming”. On the other hand, care providers who were perceived as distanced from the patient, difficult to trust or uncommitted were evaluated negatively. These results are in line with previous findings which suggest that the quality of the therapeutic relationship is an important element of ED patients’ satisfaction with their treatments (Bell, 2003; de la Rie et al, 2006; Escobar-Koch et al, 2010). Participants also described professional aspects of their care providers which they felt were negative and hindered the development of the therapeutic alliance: the little time available to them with their psychiatrists, the cancellation of appointments and the fact that professionals were at times replaced with others (due to the Salvador Hospital being a teaching facility), which patients expressed made it difficult to trust their treatment providers and made them feel as if they were “going backwards” in their recovery. This supports the notion that a positive therapeutic alliance may contribute to improving treatment adherence and outcomes (Federici & Kaplan, 2008; Gallop et al, 1994) and suggests that effort should be made to provide patients with a stable treatment team which emphasizes the development of the therapeutic relationship.

Regarding professional characteristics of care providers valued by participants, they described wanting to receive treatment from specialists in EDs. Previous studies suggest that ED literacy amongst clinicians who are not specialized in the treatment of these disorders is relatively poor. One study found that primary care physicians lacked knowledge about diagnostic symptoms, physical complications and epidemiology of EDs (Currin et al, 2009). Another study showed that health professionals with an interest in EDs but not specialized in this field did not have more knowledge about the risks and maintaining factors of these disorders than a group of patients or a sample of college students (Schmidt et al, 1995). This supports participants’ views that treatment for EDs should be provided by specialists in order to ensure the best care possible.

The fact that it is difficult to access specialized treatment within the public health system was also pointed out by participants. Chile has a public health system which serves over 70% of the population, including the poorest people in the country (MINSAL, 2006). However, few specialized ED treatment centres exist within the public system, and patients are often treated in general psychiatric facilities. Accessing specialized private care is very costly and therefore impossible for many patients. A similar situation was described by a British study in which almost 40% of participants ended up paying for private care due to the lack of specialized treatment centres within the (public) National Health Service (Newton et al, 1993), and a recent study suggested that this lack of availability of public ED Services in the UK still exists (Escobar-Koch et al, 2010). These findings emphasize the
importance of developing specialist ED services that are available to all patients and ensuring that financial constraints are not an obstacle to receiving adequate care.

Receiving treatment from a multidisciplinary team was also identified as a positive aspect of care by the participants of this study. Previous research has indicated that due to the complexity of these disorders treatment provision by a team of professionals, including psychiatrists, psychologists, experts in nutrition and social workers, is warranted, and periodical team meetings must be held to discuss each patient and agree on a treatment plan (Miranda-Sánchez, 2010). However, amongst the negative aspects of care, patients mentioned the poor coordination that sometimes existed between their treatment providers, including instances in which one health professional did not know who the other clinicians treating the patient were. This highlights the importance of not only having a group of different professionals available to provide treatment but also ensuring that they are organized and truly collaborate as a team.

The second theme which emerged from participants' responses referred to types of interventions received, and, in accordance with previous findings, individual psychotherapy was highly valued (Bell, 2003; Escobar-Koch et al, 2010; Rosenvinge & Klusmeier, 2000). Patients in this study highlighted the benefits of cognitive-behavioral techniques, in line with a recent study in which patients with bulimia nervosa and eating disorder not otherwise specified responded well to cognitive-behavioral treatments (Fairburn et al, 2009). Moreover, participants described how therapy had enabled them to understand the connection between their difficulties in expressing and regulating their emotions and their ED behaviours, and they valued help in learning “to listen to what was going on inside”, in recognizing and dealing with their emotions. This supports the notion that Emotion-Focused Therapy, which promotes the processing and expression of emotional experience, may be beneficial for the treatment of EDs (Dolhanty & Greenberg, 2009).

Pharmacological interventions were less valued than therapy by participants in this study. This supports previous findings that medication alone does not seem to be an effective treatment for EDs, due at least in part to the fact that many patients suffering from these disorders are reluctant to accept such treatment (Halmi et al, 2005). Therapeutic interventions focusing exclusively on weight gain were also evaluated negatively, in line with previous research which has identified the importance of not limiting ED treatments to issues of food and weight (Bell, 2003).

A third theme generated by participants in this study stressed the importance of feeling supported by their treatment providers during the recovery process. It has been shown that strategies focusing on support are predictors of ED patients’ satisfaction with their treatments (Clinton, 2001; Clinton et al, 2004), and it is therefore essential for ED services to provide constant support to their patients. Feeling supported by their families was also valued by participants, and they expressed concern about what they felt was insufficient communication between their care providers and their support network. Similarly, a study evaluating anorexia nervosa patients’ treatment perceptions found that many of the participants felt that their parents had not received sufficient help to support their daughters (Halvorsen & Heyerdahl, 2007). These findings suggest that ED treatment teams should have regular sessions with their patients’ families in order to provide information and guidance about how to best support them during the therapeutic process.
The final theme which stemmed from the participants’ views involved their wish for patient-centered care. In accordance with previous findings, patients identified the need for an individualized approach to treatment (Boughtwood & Halse, 2010; Escobar-Koch et al., 2010; Schaffner & Buchanan, 2008). The importance of feeling motivated and taking responsibility for their recovery was also highlighted, and participants described how becoming motivated enabled them to take on an active role in their treatment which had a positive impact on their recovery. ED patients tend to be very ambivalent about treatment and often enter into it reluctantly, and this is associated with bad treatment adherence and high drop out rates (Feld et al., 2001). In this context, finding ways to increase ED patients’ motivation becomes essential. Motivational interviewing, which stemmed from the idea that motivation is not a personality trait but rather arises from an interpersonal process (Miller & Rollnick, 1991), offers a such a possibility. Its goal is to improve patients’ intrinsic motivation to change by helping them explore and resolve their ambivalence, emphasizing personal choice and responsibility, and it has been suggested that it could be successfully applied with ED patients (Treasure & Ward, 1997, Treasure & Schmidt, 2001).

In summary, this study explored the views of Chilean ED patients about their treatments, identifying aspects that are valued by them as well as elements which they consider to have had a negative impact on their recovery. Themes generated from their responses echoed several findings from previous research, such as the importance of the therapeutic relationship, the need for treatment to be provided by specialized multidisciplinary teams, the lack of availability of specialized treatment facilities, the preference for individual psychotherapy and treatments that don’t focus exclusively on issues of food and weight, the importance of receiving support from treatment providers and family members during the process of recovery and the wish for patient-centered, individualized care. The central role of patient motivation during the therapeutic process was also highlighted. The main limitation of this study was its small sample size. The main strength was that it is, to our knowledge, the first study evaluating the views of ED patients in a South American country.

5. Acknowledgment

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6. References


Eating disorders are common, frequently severe, and often devastating pathologies. Biological, psychological, and social factors are usually involved in these disorders in both the aetiopathogeny and the course of disease. The interaction among these factors might better explain the problem of the development of each particular eating disorder, its specific expression, and the course and outcome. This book includes different studies about the core concepts of eating disorders, from general topics to some different modalities of treatment. Epidemiology, the key variables in the development of eating disorders, the role of some psychosocial factors, as well as the role of some biological influences, some clinical and therapeutic issues from both psychosocial and biological points of view, and the nutritional evaluation and nutritional treatment, are clearly presented by the authors of the corresponding chapters. Professionals such as psychologists, nurses, doctors, and nutritionists, among others, may be interested in this book.

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