Issues experienced by service users with eating disorders: A qualitative investigation

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Issues experienced by service users with an eating disorder: a qualitative investigation

Sarah Walker, Chris Lloyd

Aims: This study examined the perceptions of treatment by service users who had been diagnosed with an eating disorder.

Methods: A qualitative research design using Consensual Qualitative Research (CQR) was used. A focus group was held where the discussion was guided by a semi-structured interview schedule. Three key domains were identified using the CQR procedure: therapeutic relationship, response of others, and treatment experiences.

Conclusions: The pervasive theme that appeared to emerge throughout the session was the lack of understanding by others including family, friends and health professionals.

Key words: eating disorders, mental health, treatment experiences

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The principal eating disorders are anorexia nervosa, bulimia nervosa, binge eating disorder and eating disorder not otherwise specified. The distinction between these diagnoses is often difficult to make and there is considerable overlap between service users diagnosed with these conditions. It is not unusual for a person with an eating disorder to move through various diagnoses as his or her behaviour and beliefs change over time (Cooper and Fairburn, 1993). There is no single or easily identifiable cause for eating disorders. Eating disorders are complex conditions that are believed to result from the complex interplay of individual, interpersonal, socio-cultural, family, biological and precipitating factors (Matz and Frankel, 2005; Williams and Leichner, 2006; Warren et al, 2009).

Research in the field of eating disorders in Australia is in its infancy. It is generally estimated that in Australia 2–3% of adolescents and adult females satisfy the Diagnostic and Statistical Manual, 4th edition (DSM-IV) diagnostic criteria for anorexia and bulimia nervosa. (Wade et al, 2006; Hudson et al, 2007; Hay et al, 2008). Findings from a study of a cohort of adolescents from Victoria, Australia, revealed 8.8% of female adolescents had an eating disorder. Close to 50% of those had high levels of depression and anxiety, especially those with bulimia (Patton et al, 2003).

The Royal Australian and New Zealand College of Psychiatrists noted that the estimated mortality rate for anorexia nervosa is 12 times that of similar aged women in the community and double that of women experiencing other psychiatric disorders (Beumont et al, 2004). Follow-up studies of people with anorexia nervosa show that after four years, only 44% were rated as having good outcomes, 28% as between good and poor, 24% were rated as poor, and approximately 5% of service users had died from the disorder (Hay et al, 2006).

Treatments of individuals who have an eating disorder involves a comprehensive array of approaches. Treatment approaches may include a combination of nutritional rehabilitation, psychological intervention and medical interventions depending on the type and severity of the eating disorder (Beumont et al, 2003). Patients need to be treated with a multidisciplinary team, including a psychiatrist for pharmacotherapy and psychotherapy, a nutritionist for nutritional education and meal planning, an internist or pediatrician for medical care, and a family therapist for children under the age of 18 (Wilson et al, 1999; Wilson et al, 2002; Pike et al, 2003; Hay et al, 2004).

For the treatment of anorexia nervosa, the key elements are medical management, behaviour therapy, cognitive therapy and family therapy, while pharmacotherapy is at best an...
adjunct to other therapies (Pike et al, 2003). In bulimia nervosa, the treatment of choice is cognitive-behavioural therapy, but a greater improvement in mood and anxiety occurs when antidepressant therapy is added (Hay et al, 2004). In binge eating disorder, cognitive-behavioural therapy and interpersonal therapy produce substantial and long-lasting changes and pharmacological treatment often has a useful role (Hay et al, 2004). Overall treatment involves three basic components which include medical assessment and management, treating the psychological issues related to the eating disorder, and reducing or eliminating behaviours or thoughts that lead to disordered eating and preventing relapse.

The aim of this study was to explore the service user’s perspectives of treatment experiences.

**METHOD**

**Participants**

Participants had to meet the following criteria: an adult over the age of 18; have a diagnosis of an eating disorder i.e. anorexia nervosa (AN) or bulimia nervosa (BN); not be in the acute phase of an eating disorder; not currently receiving inpatient treatment; and not have any other co-morbidity that would impact on participation in the study. Six members (all females) met these criteria and agreed to participate in the study. Of the six participants two had a diagnosis of anorexia nervosa/ restrictive, one participant had a diagnosis of anorexia nervosa/binge/purge subtype and three met the diagnoses of bulimia nervosa.

**Procedure**

Ethical approval was obtained from the Gold Coast Health Service District Ethics Committee and The University of Queensland Ethics Committee. Participants were selected in the first instance by a database of service users who had either previously been in treatment with the Eating Disorder Adult Outpatient Service or were close to completing treatment. As part of standard clinical practice any service users accessing public health treatment for their eating disorder are also assigned a case manager to support them in any other areas of their life. The case managers were approached by the principal researcher who requested that they telephone the service user to inform them of the focus group and to obtain an initial expression of interest. Once the initial expression of interest was obtained the case manager provided the service user with the date, time and venue of the focus group. Six out of seven service users expressed an interest in attendance and an information sheet was provided outlining requirements for participation and that participation was voluntary. Service users were provided with the opportunity to sign an informed consent form. It was clearly explained to service users that choosing not to participate would in no way compromise their treatment currently or in the future.

The focus group was one hour in duration and conducted by a mental health clinician (Senior Occupational Therapist) who had previously worked as an eating disorder clinician in the United Kingdom. The focus group was audio-taped and held in a small conference room in the clinic where service users had previously attended for treatment. The discussion was guided by a semi-structured format. The following questions were used to guide the group discussions:

1. How did people around you react when they found out you had an eating disorder?
2. Were there situations in which you felt excluded or misunderstood?
3. What was/is helpful/unhelpful in treatment? (i.e. type of therapy, gender of therapist)
4. What are the barriers to treatment?

**Data analysis**

Before undertaking analysis, the audiotape was transcribed verbatim. Coding of the data involved organizing sections of the text for the purpose of further analysis. According to Seale and Barnard (1998), the purpose of coding is to bring together fragments of the text in order to create themes, which are defined as having a common element. In line with CQR, a five step process was followed when analyzing the data (Hill et al, 1997; 2005). These steps are briefly described below.

**Developing domains**

The principal researcher conducted an initial review of the transcripts and compiled a list of provisional domains. Domains are used to cluster information about similar topics (Hill et al, 1997). The initial domains were in part theoretically derived (based on a review of the literature) and in part based on material in the transcripts. The principal researcher then met with the facilitators of the focus group to review a sub-sample of the transcript so as to test the validity of the provisional domains. Following this review a consensual agreement was reached as to the final domains to be used in the analysis.

**Constructing core ideas**

The principal researcher and the focus group
leader read the transcript and organized the raw data in each domain into core ideas (Hill et al., 1997). This process aims to capture the essence of what the interviewer has said, using fewer words and with more clarity. The research team then met to discuss the findings and determine the final core ideas.

Cross analysis
The research team met to identify the typical and variant themes. Typical themes appeared in five of six participants and variant themes appeared in less than three of the six participants.

Auditing
The auditor’s role was to check whether the raw material was in the correct domain, and that all important material had been represented in the core ideas. Particular attention was made to ensure that the wording of the core ideas captured the essence of the raw data, and that the cross-analysis represented the data (Hill et al., 1997).

Stability check
The stability checking procedure recommended by Hill et al. (1997) were followed after the initial cross checking process was complete. Stability checking involves the analysis of a subset of transcripts which are withheld from the initial cross analysis. In this instance the data was limited so the initial analysis was reviewed by the team to determine whether new domains or categories were evident. As the review of the analysis did not reveal new domains or categories the findings were considered to be stable.

RESULTS
Three key domains were identified when using the CQR procedure described above: ‘therapeutic relationship’, ‘response of others’, and ‘treatment experiences’. These domains, together with the core ideas, themes and illustrative quotes are set out in Table 1–3.

Domain 1: Therapeutic relationship
Two core ideas were identified in relationship to the therapeutic relationship, trust and gender. Service users’ views are detailed above in Table 1.

With respect to trusting the therapist, Table 1 shows that service users typically viewed having a connection with the therapist as the key factor in the therapeutic relationship to assist in recovery. Participants agreed that being able to communicate and feeling a connection with your therapist, having a rapport, and not feeling judged were all important determinants as to whether they would stay in treatment, regardless of the treatment modality.

With respect to therapist gender, participants felt that females understand the pressures that they have in regard to body image and weight. One participant had experience with a male therapist in a group setting and felt that he had a good understanding of the issues. Three participants reported that they would not connect to a female therapist who ‘did not care about her appearance’. However, one participant stated ‘it would be better than a skinny therapist...that would just trigger me’.

Domain 2: Response of others
Two core ideas were identified in regard to the therapeutic relationship, trust and gender. Service users’ views are detailed above in Table 1.

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Domain 2: Response of others
Two core ideas were identified in regard to response of others: family and friends; and perceived stigma. Service users’ views are detailed in Table 2.

With respect to family and friends, Table 2 shows that families are supportive although participants state that the eating disorder (ED) creates tension and conflict within the family.
Participants reported that family members often get angry and frustrated. One participant stated that her ‘mum gets over worried, she really wants to help...but doesn’t know how to and I don’t want her to be too involved.’ Participants rarely told their friends about the ED, with the belief that they would not understand. One participant stated that at first her best friend was supportive but then got ‘sick of it’ and is no longer her friend.

With respect to perceived stigma participants agreed that the public lack an understanding that EDs are mental health conditions. They perceived that the public viewed them with ‘disgust or envy’ and often misinterpreted their low body weight as either a cause of drug abuse or attention seeking.

**Domain 3: Treatment experiences**

Three core ideas were identified in the domain of treatment experiences; attitudes of health professionals, barriers to treatment, and treatment modality. Service users’ views are detailed in Table 3.

With respect to attitudes of health professionals Table 3 shows that typically participants felt that health professionals had limited knowledge; lacked understanding and often become frustrated. Participants also made the point that when treated by specialists they felt more empathy and understanding and were more motivated to continue with treatment. One participant reported a lack of understanding by her GP who she felt thought that it was simply a matter of ‘eating more.’

With respect to barriers to treatment, participants struggled with the lack of resources and the seemingly focus on weight as a criteria for treatment. One participant felt that she didn’t really have an eating disorder unless her body weight was low enough for inpatient treatment due to inpatient BMI criteria for admission. She reported feeling a failure to the eating disorder yet her mind was ‘going mad...thinking about weight and food all the time.’ Participants felt that the Internet was a useful resource in the first instance to access knowledge of eating disorders and treatments available.

With respect to treatment modality participants agreed that problem solving and focusing on feelings were useful. Participants felt that too much focus on food monitoring was not helpful, although they acknowledged its relevance. Psycho-education was considered helpful, as well as referral to a dietician, whom they considered a trustworthy source of information on calories and metabolic rates.

<table>
<thead>
<tr>
<th><strong>Table 2. Domain 2: Response of others</strong></th>
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<tr>
<td><strong>Themes</strong></td>
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<tr>
<td>Core idea 1. Family and friends</td>
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<tr>
<td>Support of family</td>
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<tr>
<td>Social networks</td>
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<tr>
<td>Letting people know</td>
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<td>Core idea 2. Perceived stigma</td>
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<td>The public perception</td>
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<td>Understanding of EDs in the public</td>
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**DISCUSSION**

This study sought to gain an understanding of the treatment experiences of service users who were currently diagnosed with an eating disorder. In regard to the service users’ experiences the main themes that emerged from the focus groups were therapeutic relationship, response of others, and treatment experiences. The pervasive theme that appeared to emerge throughout the session was the lack of understanding by others including family, friends and health professionals. These are experiences that are commonly experienced by individuals with other psychiatric disorders. However empathy and compassion are feelings rarely evoked in others when it comes to eating disorders in com-
Research

Table 3. Domain 3: Therapeutic experiences

<table>
<thead>
<tr>
<th>Themes</th>
<th>Frequency</th>
<th>Illustrative quotes</th>
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| Core idea 1. Attitudes of health professionals |            | *Understanding and empathy* Typical *‘when I was an inpatient, I didn’t feel the doctors or staff really knew what they were doing...it’s useless if they don’t understand...you just get worse because you feel so alone.’*  
*‘At meal times they freak you out they will sit there and force you to eat...they don’t give you any empathy or help...I felt punished if I didn’t eat in a certain amount of time.’*  
*‘they don’t get it you can see the frustration on their faces...they raise their eyebrows...my GP said “don’t come back until unless you’ve gained at least a kilo”...you could tell he was annoyed with me.’*  
*Specialist knowledge* Typical *‘I was in a general psych ward, I was quite young...I was freaking out all the time because I was around people who were crazy...I was afraid and scared...I lost weight and was hiding food...they never kept a good eye on me at all.’*  
*Variant* *‘I’ve been in both a general psych ward and a eating disorder unit...I would never go back to a general ward it makes me mad...if you’re treated by staff who understand you want to change...you feel supported...and not a freak.’*  
| Core idea 2. Barriers to treatment           |            | *Access to programmes* Typical *‘It doesn’t make sense...they don’t have programs for different stages...you have to be a certain weight to get into hospital and a certain weight to have outpatient treatment...so you try and work out how to get help...usually it’s by trying to lose weight...then you are really sick...and more into the ED...I purposely lost more weight so I could go to a specialist treatment center.’*  
*Other sources of information* Typical *‘the internet is good...it helps...looking up ED websites and reading books.’*  
| Core idea 3. Treatment modality              |            | *Carer support groups* Variant *‘My parents did a carer support group...it really helped with things at home especially at meal times.’*  
*Food monitoring* Typical *‘too much time spent on food monitoring isn’t helpful...I understand it’s important but not all the time.’*  
*Other health professionals* Typical *‘it was really useful having a dietician...it made it okay to eat...knowing how your body works and all that stuff.’*  

Comparison to other psychiatric disorders (Crisp, 2005). Participants felt that the stigma associated with their illness influenced their relationships with their friends and families. Lack of empathy and understanding by others had reduced their relationships to superficial interactions. However, some theorists (Minuchin, 1974; Root et al, 1986) suggest that certain family types can lead to the development of eating disorders in some individuals, which may have influenced the results in this study. Minuchin (1974), suggested that an enmeshed family pattern often leads to eating disorders and concludes that family members are over involved in each other’s affairs and the details of their lives.

Root et al (1986), suggested that the perfect family (high achievers) and overprotective family (enmeshed family) were more prevalent with sufferers with anorexia nervosa whereas sufferers with bulimia nervosa were more likely to originate from chaotic families. The chaotic families described themselves as less involved with one another and perceived themselves as less cohesive than families described as the perfect family or the overprotective family.

However, although these early theorists had some interesting conceptualizations in terms of family types, the research has not really supported these. Current research leans more towards genetics, personality factors and coping...
skills as important factors in the development of eating disorders (Marks et al, 2003; Steiner et al, 2003; Jacobi et al, 2004; Vaknin, 2006). Despite current family dynamics the existence of meaningful relationships has long been recognized as a protective factor against psychiatric relapse (Commonwealth Department of Health and Age Care, 2000).

Overall, public responses left participants in this study with feelings of shame and embarrassment which further isolated them from others. The degree of shame has been known to vary between the various eating disorders diagnoses, for example those individuals with bulimia and binge eating typically associate more shame and embarrassment due to the perceived lack of control by others and themselves (Escobar-Koch et al, 2010). Whereas those with anorexia nervosa perceive less shame and embarrassment as they may view their disorder as superior to others which is often reinforced by western society that equates thinness with beauty, control and success (Escobar-Koch et al, 2010). Consequently, individuals with anorexia nervosa can be extremely ambivalent and resistant to change which can be challenging for families and health professionals. However, the participants in this study felt that the response of others reinforced their self-perception as being ‘failures’ especially in the respect that their disorders are self-inflicted, with all participants sharing that others lacked understanding and empathy. This finding highlights the need to provide education to both families and the public to reduce the stigma attached to EDs (Crisp, 2005; Escobar-Koch et al, 2010).

Even more concerning is that participants had experienced poor relationships with their health providers due to the health professional’s lack of understanding about the disorder. As such, participants felt they lacked trust in the skills of the health professional. Given that previous research has suggested that a negative therapeutic alliance contributes to service users dropping out of care, this highlights the importance of providing health professionals with adequate training and support to develop their skills (Gallop et al, 1994; de la Rie et al, 2006; Escobar-Koch et al, 2010). The importance of working to understand and eliminate the blame-based stigmatization of EDs cannot be overstated. The preference for being treated by specialist staff appeared to enhance their motivation to attend treatment as found in other studies (Escobar-Koch et al, 2010).

The therapeutic relationship seemed important to participants in terms of remaining in treatment. Not surprisingly, having rapport with the therapist created trust between the service user and therapist and was expressed as the most important criterion for the quality of the therapy of eating disorders (de la Rie et al, 2006). This poses the question that although we can conclude that the non-specific components of therapy are the most important, it appears that therapy itself may be ineffective or below placebo threshold. In terms of therapeutic interventions, participants who had received inpatient care spoke of the punitive environment and lack of understanding by staff. Participants expressed concern over the skill base of the staff, reporting that they felt pressured or punished if they did not eat and staff lacked empathy for their illness. The implication of this, points to greater access to specialist services or at the minimum more access to training and support for staff. A further important factor related to inpatient treatment was the lack of sharing of information, between staff and family members. Participants expressed how family members relied on the service user to keep them informed of treatment management, which created stress and tension between family members.

It would appear that consideration of sharing information with family members would be of benefit in supporting the family system and reducing the pressure on the service user. Previous research has shown that carers are dissatisfied with the amount of knowledge they have and want more information about their family members (Hodgson et al, 2002; Scharer, 2002). However, it is recognized that although some users might find the sharing of information helpful, others may find it less so. This latter group might like to keep information about their care from their families for different reasons, such as, a sense of control, ambivalence about making changes, and avoiding further family conflicts to name a few. Great caution and serious consideration are needed by the treating team in order to strike a balance between the user’s ambivalence, confidentiality issues, and the needs of the family.

As expected participants least liked being weighed and recording food monitoring, although participants acknowledged that both of these strategies are relevant. Previous research has also found that the structure of treatment including being weighed and charting food intake is a deterrent to treatment compliance as service users invariably feel pressured to try new things such as increase weight of which they feel ill equipped to manage (Rosenvinge...

The importance of this is the awareness that participants typically dislike the activities considered essential in treating service users with an eating disorder. Additionally, it highlights the importance of the therapeutic alliance in order to support the service user in compliance to the fundamental aspects of treatment; being weighed and monitoring food intake.

LIMITATIONS AND FURTHER RESEARCH

There are a number of limitations associated with this study. Firstly, the sample of participants in the focus group consisted of six females and, as such, the generalizability of the findings is weak and cannot be generalized to all service users with an ED. Secondly, all participants were from the same geographical area and as such had often received treatment that was not specialist in nature. Thirdly, the small sample limited the capacity to identify differences by social economic status (SES), ethnicity, age, and psychiatric history. Also, is cannot be ignored that social desirability may have influenced responses, due to the known sensitive traits of the participants and their need to ‘please others’. Their desire to fit in and be part of the group may have restricted their responses. In addition, the competitive nature of those with an eating disorder is well documented and may have prejudiced some participants’ responses.

Although this study found the therapeutic relationship as an important factor it does not assume that the perceived relationship with the therapist is the only factor which determines recovery outcomes. Assertive treatment that challenges cognitions to target inaccurate thinking, as in cognitive behavioural therapy, as well as a stronger relationship with clinicians may produce a more positive experience of treatment and attain better recovery outcomes. Further research in this area is needed to include a larger population and mixed genders. It may be that male sufferers have different experiences of treatment providers due to the perceived perception that eating disorders are a ‘female’ disorder.

Despite the limitations, the findings provide a snapshot of perspectives of service users that appear to concur with other studies, in terms of perceived inpatient punitive treatment, lack of knowledge and empathy from some health professionals, and dislike of the more specific behavioural interventions such as food monitoring and regular weighing (Gallop et al, 1994; Rosenvinge and Klusmeter, 2000; Swain-Campbell et al, 2001; Hodgson, et al, 2002; Scharer, 2002; de la Rie et al, 2006; Escobar-Koch et al, 2010). It has also provided insight into the importance of the therapeutic relationship and adequate training for staff.

CONCLUSION

The present study found distinct themes emerging from the service user focus group. These themes included the therapeutic relationship, response of others (family/friends/health professionals) and treatment experiences. Not surprisingly, the quality of the therapeutic relationship cannot be understated, as a crucial factor for providing empathy and support during the recovery process. The response from others highlights the need to provide intervention specifically targeting the effects of stigma such as carer support groups and community education. This modest study has highlighted the need for further research and the necessity to enhance the knowledge and understanding of eating disorders among treating teams and the families of the clients. Although this was a small sample this research highlighted aspects of the clients’ experiences, that can be targeted in a positive manner to improve the professional skills of health professionals, enhance the therapeutic relationship and experience, and move towards better outcomes in this challenging clinical area.

KEY POINTS

- Between 2–3% of adolescent and adult females have anorexia or bulimia nervosa.
- There is not one single cause of developing or having an eating disorder.
- Treatment approaches involve a comprehensive array of approaches.
- A qualitative research design using Consensual Qualitative Research was selected for this study.
- The aim of this study was to explore the service user’s perspectives of treatment experiences.
- Three domains were identified. These were therapeutic relationship, response of others, and therapeutic experiences.

Hodgson O, King R, Leggatt M (2002) Attitudes toward eating disordered participants felt misunderstood and judged by relatives and professionals. This was associated with withdrawal from social relationships, increased isolation and superficial interactions with others. A third main finding was that the participants emphasized their preference for being treated by trained professionals rather than by mental health carers who were not trained to treat ED specifically.
Change and emotional safety
Many patients with ED are ambivalent about the process of recovery for many different reasons. This therapeutic process requires major behavioural changes and exposure to situations and ideas, which are emotionally distressing for the patients. I will argue that creating an emotional secure environment is essential for the patients in order to engage in this difficult process. The results of this study illustrate how different elements of therapy can promote or challenge the patients’ perceived emotional safety, and in turn influence their experience of treatment; trust, identification and feeling understood, were all related in this study to feeling emotionally secure in the therapeutic relationship. On the other hand, when participants felt misunderstood and judged by relatives and professionals, they described the unsafe emotional experiences of isolation, shame and abandonment. Retrospectively, par-
participants reported a strong affinity towards the prospect of treatment by trained professionals. It seems as if the mere thought of being in good hands contributed to feeling emotionally secure even before treatment actually began. Emotional safety seemed also to be enhanced when patients were thoroughly guided about their nutrition and when they were kept an eye on. These elements of treatment were referred to as unpleasant, but necessary and sometimes even welcome.

Like ED patients, patients suffering from anxiety disorders are also required to engage in exposure to situations that evoke unpleasant thoughts and emotions. Therapists working with such patients are usually very aware of creating a non-judgemental, supportive, and emotionally secure atmosphere. If possible, these therapists externalize the problem, so that the therapist and patient can stand side by side to fight the problem, instead of each other. Somehow, when working with ED, doing exactly this seems to be very difficult, and in my eyes, this is what the participants in this study seem to describe.

**Conclusion**

This study highlights how difficult it is to create an emotionally secure framework when working with ED patients. Professional training, supervision and insistence on the creation of an emotionally secure environment are essential for successful treatment of patients with ED. Understanding the factors that cause and maintain ED is also essential, so that patients and professionals avoid stigmatization and blame, and can fight the illness together.

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**Research**

“The results of this study illustrate how different elements of therapy can promote or challenge the patients’ perceived emotional safety, and in turn influence their experience of treatment; trust, identification and feeling understood, were all related in this study to feeling emotionally secure in the therapeutic relationship”

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