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Revisiting current approaches of treatment and outcomes.
The users' perspectives

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Abstract

A qualitative exploratory study had been conducted in community-based centers that have developed non medical treatment approaches and programs for people who have profound disorders of thought, emotions and relationships. This report focuses in the users' perspective. It addresses the complex issue of improvement and change associated with the treatment. The users views about their treatment experiences were documented through semi-structured interviews. Users' narratives describe different forms of improvement and change associated with their attendance at these community treatment centers. The transformations evoked cluster around a few recurring topics: the experience of oneself, the relationships with others, the reasons for living and their personal stance towards the common world. The findings of this exploratory study put forward a number of indications both for psychiatric practice and research. They confirm the importance of reinforcing holistic and human approaches to treatment. Similarly, they suggest that outcomes studies need to give an important place to qualitative methods giving access to the users' subjective experience of change and allowing to situate them within a larger life-frame.

Key words: Treatment, outcomes, change, subjective experience, therapeutic environment, qualitative research

Revisiting current approaches of treatment and outcomes.

The users' perspectives

Since the second half of the twentieth century, important developments in psychotropic treatments have had many significant impacts, in different ways, both on psychiatric research and psychiatric practice. On one hand, for many people with severe mental disorders, these developments, by reducing positive and acute symptoms, have permitted them to leave psychiatric institutions and live in the community (1-2). On the other, the generalization of psychotropic treatments in psychiatric practices has contributed to simplify and to narrow the comprehension and approaches of psychiatric treatment as aimed by action on symptoms (3-5). Both the goals and means of psychiatric cure have been seriously affected (6).

Similarly, in psychiatric research, outcomes studies have largely focused on symptoms and the variables affected by changes in symptoms, hospitalisation rates and social functioning (7-8). For studying these variables, researchers have developed standardized methods (9). Although recognizing the importance of more objective variables and methods, some authors have argued that they are not sufficient to give access to the complex issue of improvement and change for persons who have profound thought and emotional disorders (8,10-12). Subtle changes and subjective dimensions and experiences of improvement and change requires the development and use of other methods (7, 13). These methods are largely qualitative and have their specific instruments of data collection and ways of data analysis through the immersion into the material and an attention to subtle and countless dimensions. In recent decades, the recovery movement has significantly contributed to promote qualitative research in psychiatry and,

especially, to give an audience and voice in psychiatric research to people living with severe mental disorders (1, 14-15).

Most of the outcomes studies have another limitation, again pointed to by different authors. These kind of studies have often neglected the important issue of parameters and factors in the treatment modalities and processes that influence outcomes and contribute to positive changes for people with severe mental disorders (8, 16-17). From this perspective, it appears particularly important to explore the question of the dimensions of a treatment approach which are clinically relevant (18).

In a recent qualitative exploratory study pursued in Quebec (Canada) within community-based treatment settings, we addressed these two issues. The present report focuses on the users' perspective and is articulated around two questions: What do amelioration and positive change mean in the users' narratives? What aspects of the treatment and treatment setting do the users evoke to explain amelioration and positive change?

Method

The study has been conducted in community-based centers that identify themselves as specialized in the treatment of mental health problems. In each setting, interviews were conducted with both users and staff about their respective perception of different aspects of the treatment program and about its effects and results on users (19-20). This paper is centered on users' narratives.

Settings

The study took place in nine community-based treatment groups, situated in both urban and semi-urban areas. These centers call themselves *Alternative Treatment Resources in Mental*

Health. They share an alternative philosophy of treatment which focuses on the human and social dimensions of mental health problems and promotes the respect of persons' rights, consumers' participation and civil citizenship issues in mental health field and practices (21-22). Institutionally, alternative treatment resources are independent from the psychiatric system, but they are recognized and financed by the public administration. Concretely and in specific cases, they may collaborate with psychiatric services for the follow-up of particular patients. It should be noted that the great majority of the users of treatment alternative resources have also received or receive psychiatric treatment.

These alternative centers have developed non-medical treatment approaches and programs for people who have profound disorders of thought, emotions and with relationships. They offer individual and group therapies, verbal and non-verbal; a treatment dimension is attached to formal as well as informal settings provided by the centers. Their approach to treatment has psychoanalytical, psychodynamic and humanistic inspiration. Some centers offer day treatment programs; others offer residential treatment programs. Depending on the centers, the programs are intensive and short-term or long-time oriented; program duration varies between eight months and five years.

Subjects

Two users were recruited in each of the nine settings (one user per case). In each center one of the users had already completed the treatment program, while the other was still in treatment, though almost completed. Ten women and seven men, between thirty and sixty years old, participated in the research process. All the narratives evoked severe mental disorders involving an intense personal suffering and disturbances of thought, emotions and in relationships. All but one person had experienced psychiatric services and medical treatments,

most being hospitalized for mental health disorders, sometimes for long periods of time. According to the philosophy of the Alternative Treatment Resources (21-22), it was not possible to inquire directly about the users' diagnosis. However, most of them spontaneously mentioned having received a psychiatric diagnosis while they were in psychiatric treatment; including schizophrenia and related disorders, personality disorders, bipolar troubles, severe depression.

For the recruitment of subjects, the research team asked the director of each center to present, without pressure, the research objectives and procedures to current and past users. The role of the directors in the process stopped there. The users interested in participating had to contact the research team directly.

Collection of data

The users views about their treatment experiences were documented through semi-structured interviews. This method allowed us to explore a set of specific sets of questions we had in mind, while also giving a large degree of freedom of expression to the interviewees. Informed written consent was obtained from all participants. One individual interview was conducted per participant. The duration of the interviews were between one hour and thirty minutes (1:30) and two and a half hours long. The interview grid addressed different areas: the context of the user's arrival at the center and the quality of the reception; the treatment program offered in the center and the user's perception of the therapeutic process and of its key turning points; the most helpful aspects and limits of the program as perceived by him or her; the relationships with therapists; their perception of the specific impact of different aspects from within the range of activities provided at the center; the user's more general therapeutic trajectory. All interviews were taped and then systematically transcribed (verbatim). Pseudonyms

were used in the transcript and during analysis; the centers were not identified in the presentation of results.

Analysis

The qualitative data collected from users were dense and rich. We treated the data collected from each person as forming a narrative versus isolated responses to specific questions. We read these various narratives comprehensively in order to progressively determine the large analytical categories emerging from the respondents' narratives as well as the particular topics constitutive of each category. The following categories were identified as follows: atmosphere in the center; philosophy of the treatment program; therapeutic principles; organisational aspects of the program (attendance conditions, formal and informal settings, common rules, etc.); personal objectives; changes associated with the attendance in treatment activities and in other activities at the center.

The analysis procedure followed a double direction. On one hand, to be able to compare data pertaining to the different categories, the content of each verbatim was systematically re-organized with respect to the six items mentioned above; excerpts were reproduced and arranged in tables in order to give clarity to the particular topics associated with each category. On the other hand, to maintain the uniqueness of individual users' experience, we systematically consigned the portions of the narratives, comments and details pertaining to subjective experiences and to personal trajectories. The present paper focuses on this final section of the analysis.

Results

Users' narratives describe different forms of improvement and change associated with their attendance at these community treatment centers. It is striking to see how these narratives give little or no place to traditional indicators of improvement, like attenuation of positive symptoms, reduction in the frequency of hospital admissions, positive changes in social functioning. Instead users' narratives repeatedly emphasize other types of change that are significant for them. Three case vignettes will illustrate the users' perspective. We will then discuss their significance and propose a synthesis of the main dimensions of improvement and change mentioned by the users as well as the elements of the program that they see responsible for these changes.

Case vignettes

Case vignette 1. Mr. L., a 60-year-old man with "serious schizo-affective illness" (according to his own words), mentions having been affected by this disorder relatively late in life. He links the emergence of his mental health problems to his "very sensitive personality" 1 and to his difficulty of living in such an aggressive and cruel world. He describes himself as having been obsessed for a long time by the "terrible reality of war" and by an internal fight between "violence and peace, fury and love". For many years, he was frequently hospitalized and took significant doses of psychotropic medication. He started to attend the alternative treatment resource five years ago. It took several months for Mr. L. to begin to leave his isolation and become able to engage himself in therapies and group activities. Nevertheless, he preferred not participate in individual therapy. At the time we met him, he worked as a trainer in an art atelier at the center. As showed in his

narrative, Mr. L. has experienced some important changes during his stay at the center. Progressively, he discovered confidence and pleasure in relationships with others, both in the context of group therapies and in more informal settings. He learned to connect with others while respecting the personal boundaries that were so fundamental for him. For more than two years he became involved in art-therapy group sessions; this verbal treatment allowed him to come to terms with obsessions that were invading his life and, little by little, he was able to cope with these obsessions. After, he felt more peaceful with himself and the world. During the art-therapy sessions, he "re-discovered a simple and gentle well-being". He describes the center environment as a non-stressful one, where his own rhythm was always respected. Mr. L. has not been hospitalized for a few years and his medication has been seriously reduced.

Case vignette 2. Ms. M., a 45-year-old woman, describes with detail a severe depression and repetitive psychotic episodes that she had endured for many years. She was often hospitalized, in conditions that she describes as having been "extremely painful" for her. She had to take significant doses of psychotropic medications. She recalls that when she arrived at the alternative treatment resource four years ago, she felt very miserable, experiencing intense suffering and being completely "lost". She evokes an important but long process of change that she experienced after her arrival: "I feel I am always progressing, always progressing even if sometimes I fall". The process of change has affected her experience of herself and her vision of life in different ways. Through the regular and authentic contacts she established with a therapist, Ms. M. has "learned, for the first time in (her) life, to give (her) confidence and to be in relationships". This was for her a completely new way of developing relationships with others. Besides this important dimension of change, Ms. M. evokes a profound internal experience in which she has felt being more "transparent", and "genuine": "I come nearer and nearer to who I

am, who I am really.” In regard to her voices and delusions, she developed a new, less painful attitude: “they are part of me and I could cope with them”. “If I escape, they will return by other ways”. This new stance helped Ms. M. to develop a more positive perception of herself: “I have a value, an human value even if I do not have a full time job.” Concretely, she has joined actively a rights defence group as a volunteer. Several times in her narrative, Ms. M. insisted on one important point: the improvement and changes that she has experienced since her admission to the treatment center have been made possible by the range of opportunities offered to her in this place: individual and group therapies, meaningful therapeutic relationships, informal activities and settings, a sense of “coherence” and “transparency” that she associates with this environment. She notes that she no longer needs high doses of psychotropic medication and that she has not been hospitalized for four years.

Case vignette 3. Mr. D., a 30-year-old man, was hospitalized for several months for psychotic acute problems and drug abuse, just before coming to live at the residential treatment setting. At this time, he was “completely lost” and harassed by “malevolent voices”. He remained at the treatment setting for one year and half although he had left it one year before to live in an independent apartment. Once a week a worker from the treatment center visits him. With this help, he is now trying to obtain the right to visit his young daughter. At this stage in his life, Mr. D. has found a kind of stability; he follows, part time, a photo graduate course and composes music and poetry. He regularly continues to informally visit the Alternative Treatment Resource and describes it as “my base”. His narrative indicates that the residential center has contributed to his improvement in different ways. Learning to “verbalize” his “voices” in individual therapy has allowed him to better “control” them. His relationships with therapists, in both formal and informal contexts, have helped him to “think and speak more clearly”, “with the right words”. In

his narrative, Mr. D. describes himself as being deeply eager to more genuinely encounter others. For a long time it was almost impossible for him to communicate with others: “I had begun to try to communicate with therapists and after I could communicate with other users. I shared with them both simple pleasures and also pain and inner experiences.” In his narrative, Mr. D. evokes several times the quality of the atmosphere in the treatment setting; he found in it a “good home”, “where the air was pure and relations peaceful”, qualities which have helped him to become progressively more confident in the world and in his own place in the world: “Today, I feel adopted by the planet”.

Users’ perspectives on improvement and change

This collection of individual users’ narratives allows us to rethink the complex issue of improvement and change for persons with severe mental disorders that, in most cases, affect thought, emotions and relationships. The transformations evoked by the persons we met are clustered around a few recurring topics and can be grouped together under four main dimensions that describe the changes that the users perceive as essential and as having been accomplished with the support of the treatment center: 1) the experience of oneself; 2) relationships with others; 3) reasons for living; and 4) their personal stance towards the common world.

Experience of oneself Users’ narratives suggest that mental disorders imply both a profound alteration in the experience of the self and a difficulty in establishing a deep relationship with oneself. In most cases, the changes evoked along that dimension involve the possibility for the person to encounter his or her own personal suffering: “I have learned to not escape any more from my suffering.” (Ms. V.) “I needed to confront it seriously.” (Ms. J.) “I have learnt to put words on my suffering.” (Ms L.) This new attitude is often perceived as the first step in a broader

modification of the experience of oneself. The main changes in the relationship to oneself occur along two main pathways. For a number of persons, it implies the capacity to reach the “true” self which had been hidden for a long time: “I had lost who I am.” (Ms. V.) “I no longer have a mask.” (Ms. A.) For other persons, the change involves the emergence of something that did not exist before: “I have discovered I would like to be but I was not.” (Ms. J.) “I have built myself. Previously, I was like a house without a basement.” (Ms. L.) “I was a puddle of water. Now, I am someone.” (Mr. D.) Another change evoked in a large number of users’ narratives consists in a sense of the re-opening of the self: “I have gotten *branches* of myself.” (Mr. D.) “I feel more and more free in myself.” (Ms. F.)

Relationships with others Narratives indicate that relationships with others are often a core aspect of the experience of the disorder and of personal suffering. Similarly, relationships with others appear fundamental to the experience of improvement and change. Several users evoked the difficulty they had connecting with others they perceived as hostile, dangerous or indifferent, and by contrast, the new experience of relating with others that they had developed with the support of the treatment center. A woman remarked: “Before I always felt danger with regard to other people. Today, I feel safe and comfortable.” (Ms J.) As was the case in Ms. M.’s narrative, a number of narratives evoke the progressive development of a new mode of relationships, which implies an emergent sense of confidence, unknown before, in others and its impact on the reinforcement of the self. A woman recalled: “For the first time, I accepted to receive consideration and love from other persons.” (Ms G.) More largely, users’ narratives denote a change in their general attitude toward others and the development of a greater tolerance.

Reasons for living In most cases, users' narratives are sober when evoking the details of their personal experience of suffering. Nevertheless, they clearly indicate that a deep sense of depression, the loss of reasons for living and hopelessness are, for many persons, an integral part of the experience of mental disorders. For Ms. M.: "Depression was my own way to live and to be." But, she also described, as others users did, the unique experience of discovering reasons for living: "I saw my life, my future and the whole world as invaded by destruction and death. Now, I see my future as surrounded by the others and by life." Another woman commented that she has "found again a conversation with life" (Ms N.). Some narratives are more concrete in their description of new reasons for living. They mention the discovery or rediscovery of interests, even of passions. They evoke the capacity to formulate projects for their present life and for the future, the capacity to project oneself. A man remarked: "I did not have any projects before. Now I have a lot of projects." (Mr A.)

Personal stance toward the common world Self-isolation and a sense of exile, often redoubled by objective factors of exclusion, are experiences that appear to be intrinsically linked to severe mental disorders; they often constitute for the users an additional source of suffering. However, the narratives also illustrate different paths and trajectories through which users developed a more satisfying attitude toward the common world, especially the social world. Although not the majority, some narratives, insist on the ability, now effective, to obtain a place in the "normal" world of work: "I need to work again to feel really recovered." (Ms. F.) Other narratives mention a different experience of a direct and concrete involvement in and for the common world that develops outside the paid work system: militancy in human rights groups, creation of support groups, voluntary work for helping vulnerable people. "I feel I am now able to do good to others" remarks Mr. L.. A few narratives evoke clearly a form of detachment from

the social pressures and criteria associated to a normal functioning: “I am first in quest of a place to fulfil myself.” (Ms. V.)

Users’ perspectives on reasons for improvement and change

When users comment on the causes for such improvements and changes, they never mention just one specific aspect of the treatment program. The possibility of following a specific therapy or the quality of the relationship with a therapist never appear sufficient in themselves for explaining how the treatment program affected and modified their personal trajectory. Instead, users’ narratives indicate that there were a combination of factors that contributed to their improvement and changes. Five factors appear especially relevant: 1) the opportunity to experience security and stability in the treatment setting; 2) the positive reflection of oneself experienced in the treatment setting; 3) the opportunity to build meaningful relationships with others; 4) the opportunity to go through an in-depth personal transformation; 5) the multiplicity of the opportunities available in the treatment center. Narratives rarely establish a hierarchy between these aspects. Users seem more concerned by the connection between these factors or their global effect.

Opportunity to experience security and stability The quality of the atmosphere of the treatment center is repeatedly mentioned in users’ narratives; its various dimensions are specifically touched upon as having contributed to the processes of improvement and change. The dimensions of security and stability appear fundamental in that context. A number of narratives illustrate that persons found in the treatment center a solid basis for life, both real and symbolic, a “home” that has become an essential element in their therapeutic trajectory: “I found there a global feeling of hospitality.” (Mr. A.) “I was secure there. It had been an important reason in my recovery.” (Ms. L.) Users’ narratives describe a cohesive and reassuring

environment and suggest that it significantly contributes to helping persons suffering gain access to an inner experience of security and stability and to interiorize them. More importantly, the narratives evoke the impact of the global coherence of the treatment setting: “There is a real coherence between principles and acts”, remarked Ms. M.

Positive reflection on oneself Most users’ narratives insist on the importance and the positive impact of the reflection of oneself that was supported by the Alternative Treatment Resource: “I have been completely accepted. I was Ms. L. and I will be always Ms. L. for them. They never used my psychiatric diagnosis.” (Ms. L.) “The therapist never perceived me as ugly as I perceived myself. She saw a most profound part of my self.” (Ms. N.) “I felt that the therapist believed in me, believed that I could improve and I could do something good with my life.” (Mr. A.) This positive reflection of oneself is often presented as being reinforced by the concrete opportunities offered by the treatment center; users have the chance to initiate and to develop personal projects, to engage themselves in different committees, to organize and to be in charge of group activities. Users’ narratives illustrate the importance and the impact of the idea of the “human being” promoted in the treatment center: “The human being comes before a sick person” (Ms. M.), “a human being with his forces and with his weakness” (Ms. F.).

Opportunity to experience meaningful relationships with others Users’ narratives show that alternative treatment settings offer substantial opportunities to experience relationships with others, both in formal settings like group therapies and in more informal settings like social activities: “We were always in group.” (Ms. V.) “The social life was very rich.” (Ms. G.) Users’ narratives suggest that the user’s ability to develop relationships with others represents a fundamental goal of the treatment program, which addresses the issue in different ways.

Narratives emphasize various experiences of meaningful relationships both with the therapists and with other users. In the first case, users describe how the real presence and the genuineness of the therapists opened for them the possibility of a form of proximity in interpersonal relationships: “In our encounters, I felt that therapist was genuine and true.” (Ms. N.) In the second case, users evoke the importance of a sense of solidarity and comprehension between users: “I found there a comprehension rarely found before.” (Ms. E.) These experiences of meaningful relationships with others are described as having contributed to the process of improvement and change in the relationships with both oneself and others.

Opportunity for an in-depth experience of oneself The treatment program is first described as a place where it is possible to experience an in-depth encounter with oneself: “to go in-depth in the suffering” (Ms. B.) , “to travel in the quest of oneself” (Mr. A.), “that is the unique way to recover” (Ms. J.). This opportunity is perceived as the first goal of the treatment program. Users’ narratives show that such a personal experience may happen not only in the formal context of therapy but also in less formal settings. Some users arrived with the desire for this kind of personal deep engagement: “I came here for it” (Ms. F.), while others did not, sometimes suffering for wanting it: “I would like just stop suffering. It was later when I began thinking about it.” (Mr. A.) Users’ narratives illustrate that the treatment setting is flexible enough to adapt to different personal patterns and difficulties. Several users insist on the program’s consideration for the uniqueness of the person. A woman remarked: “They adapt the treatment program to each person. There is no person that is similar. They always consider that issue.” (Ms L.)

Multiplicity of the opportunities in the treatment setting The multiplicity and the richness of the opportunities found in the treatment setting are omnipresent in users’ narratives: “Diversity and multiplicity had been so important for me.” (Ms. N.) “For me, all aspects have been

significant.” (Ms. G.) “I came there for changing some things, but I did not think that the changes would be so numerous and so great.” (Ms. F.) Users evoke the contribution of verbal therapy and other forms of therapies, like art-therapy and corporal therapy, individual therapy and group therapy, formal therapy and more informal activities and settings, and the center’s atmosphere. Their narratives show that in an alternative treatment setting users have the opportunity to address both personal difficulties and the multidimensionality of a human being, to experience suffering as well as recovering, as well as a “home” to reassure themselves and an opportunity to engage in an exigent and often long personal process of transformation.

Discussion

Our findings are in concordance with other studies which address the complex issue of improvement and change associated with the treatment of mental health problems that deeply affect thought, emotions and relationships. Their studies highlight the importance of considering the point of view of the persons affected by these problems (13, 23-24). In users’ narratives, change and improvement appear complex and multidimensional. In itself, change takes a double significance; it is sometimes presented as an evolution and sometimes a transformation. Users’ narratives illustrate that change is always primarily a profoundly personal experience.

The findings of this exploratory study put forward a number of recommendations for both psychiatric practice and psychiatric research. At the level of practice, they suggest that treatment programs with restrictive goals are too limiting to address the subjective dimensions of psychiatric disorders. From this perspective, treatment programs aimed mainly at symptom alleviation are restricted if not inadequate. Users’ narratives clearly indicate that changes in symptoms are in themselves not sufficient. Moreover, they illustrate that there are various ways to deal with symptoms, as illustrated in the cases of Ms. M. and Mr. D. For Ms. M., symptom

improvement is associated with a new understanding of her symptoms as seen as a part of herself. In the case of Mr. D., the important thing was for him to find a way to make his symptoms less invading through controlling them. Practices should be flexible enough to adapt to the various and profoundly personal ways people relate to their symptoms and to support their singular ways of dealing with them.

Another important question for psychiatric practice raised by users' narratives was the necessity to enlarge the understanding of the improvement in social functioning as a treatment outcome. The subjective stance people take toward the social world should be integrated within the understanding of the processes of improvement. From the person's point of view, a positive outcome is not necessarily associated with a return to normality; it can imply a range of stances toward the social world, including volunteer involvement and forms of detachment from normative pressures.

More substantially, rejoining an old psychiatric tradition, the study's findings bring out the integrated contribution of the various components of a specific treatment setting to the improvement and experience of change (16, 25-26). They confirm the importance of reinforcing holistic and human approaches to treatment (4, 11). Indeed, the general characteristics of the environment setting such as stability and security, a focus on relationships, informal interactions and activities in formal settings such as individual and group therapies, all appear fundamental to users' narratives. The crucial issue is the way in which the different components of the treatment programs are brought together and made flexible enough to adjust to individuals. The narratives illustrate clearly that a key condition lies in the encounter of a consistent and human treatment approach with an active and coherent treatment *milieu*.

Other implications of the findings concern research methods. They illustrate that objective approaches are insufficient to capture the users' point of view on outcome; they should be

completed or counterbalanced by qualitative approaches which allow access to users' experiences and wishes. Users' narratives clearly show that what counts as valuable treatment outcomes cannot be measured by standardized scales, that there are important and significant changes that cannot be approached by objective methods. Outcomes studies need to give an important place to qualitative methods that give access to the users' subjective experience of change and improvement, thus allowing to situate them within a larger life-frame. Some authors have argued that subjective experience has an influence on both the course and treatment of psychiatric disorders (10, 13). In addition, it appears important to develop methods and instruments that permit for an adequate consideration of the contribution of different therapeutic components of a specific treatment program.

There are a number of limitations to our study. The number of participants is limited and they are not homogeneous from a psychiatric perspective, although all users, except one, had received a diagnosis of a severe disorder. The settings are also not homogeneous in terms of the program's duration. Moreover, alternative treatment settings are not representative of current treatment programs in psychiatry. Complementary studies should also explore other psychiatric treatment settings such as day hospitals. It would also be important to explore whether a specific type of treatment program, with specific features in terms of intensity and duration, appears best suited for a particular type of psychiatric disorder. To investigate these issues, we have recently initiated a study in four day hospital programs, both specialized (severe personality disorders and psychotic disorders) and non-specialized. Another important research issue concerns the distinction between changes having only a short-term impact and those which have more long-term effects.

Undoubtedly, users' narratives from alternative treatment resources invite us to enlarge the issue of treatment both in psychiatric practice and in psychiatric research.

Note

1. All excerpts were translated from French by authors.

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