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Abstract

Background: International guidelines recommend planned and structured transition programmes for adolescents with chronic illness because inadequate transition may lead to poor disease control and risk of lacking outpatient follow-up.

Objective: To investigate the feasibility of a transition intervention aimed at adolescents with chronic illness focusing on declines, drop-outs, no-shows and advantages and disadvantages of participating.

Methods: We invited 236 adolescents (12–20 years) with juvenile idiopathic arthritis (JIA) to participate in a randomised controlled trial (RCT) transition intervention. Reasons for decline and drop-outs were calculated. Adolescents' experiences of advantages and disadvantages of participating and reasons for no-shows were investigated through focus groups and telephone interviews, which were analysed using thematic analysis.

Results: One hundred and twenty of the 236 eligible patients declined to participate in the intervention and 20% dropped out during the intervention. Unspecified declines and practical issues were the most common reason to decline, and 'do not wish to continue' was the most common reason to drop-out. Reasons for no-shows were forgetting and being too busy. Advantages of participating were stated as 'participating without parents', 'trust and confidentiality', 'being able to set the agenda'

and 'responsiveness'. Disadvantages were 'unclear aim of the study', 'meeting others with JIA', 'too few conversations' and 'transport issues'.

Conclusions: Many adolescents had difficulties understanding the aim of the intervention. However, most participants appreciated the conversations about identity as well as the trust and confidentiality in the communication. In the future, adolescents should be offered more individually organised programmes according to their preferences and needs in cooperation with parents and health care providers.

Keywords: adolescents; chronic illness; feasibility; intervention; transition.

Introduction

'Transition is an age and developmentally appropriate process, addressing the psycho-social and educational/vocational aspects of care in addition to the traditional medical areas' (1). Inadequate transition, including transfer from paediatric to adult departments, has been shown to cause poor disease control (2, 3) and a lack of outpatient follow-up, which may lead to serious long-term consequences (4–6). Research indicates that supporting adolescent autonomy as well as motivational support and behaviour-centred interventions by health professionals may increase adherence in adolescents with chronic illness (7). As some of the adherence barriers in adolescence are associated with psychosocial development (8), structured transition programmes may further support adolescents' treatment adherence.

Research in the field and consensus guidelines recommend that transition programmes should preferably contain: a multidisciplinary approach, routine split visits (individual consultations without the parents being present during the first part of the visit and with parents in the latter part), longer consultations than usual, screening for behaviour that poses health risks, autonomy support, trust-building communication, and conversation on non-medical aspects of the adolescents' lives (9–14). We designed a transition programme TUBA (Danish: Transition for Unge i Børnereumatologisk Ambulatorium/English: Transition for Adolescents in Paediatric

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Rheumatology Clinic) as a randomised controlled study for adolescents with juvenile idiopathic arthritis (JIA) based on the above criteria. Adolescents with JIA were chosen for the intervention, because they are challenged by the same level of non-adherence and experience the same barriers to medical adherence as other adolescents with chronic illness. Furthermore like many other chronic illnesses JIA may complicate a normal everyday life because of pain and restricted physical capability and it is not easily identified by outer appearance.

Some studies have indicated that it can be difficult to recruit participants and especially young patients to scientific studies (15), and that adolescents have a high rate of no-shows in outpatient clinics (16, 17). To improve our understanding of how to recruit and keep adolescent patients in a transition programme, and how to design future acceptable, relevant and sustainable transition programmes, we performed a feasibility study. The aim of this study was to investigate the feasibility of a transition intervention aimed at adolescents with chronic illness. We asked the following research questions:

1. What reasons do adolescents with chronic illness give when declining to participate in the TUBA intervention?
2. What reasons do participants give for dropping out of the TUBA intervention?
3. What advantages and disadvantages do participants in the TUBA intervention experience?
4. What reasons do participants give for no-shows in the TUBA intervention?

Materials and methods

The TUBA intervention

The randomised controlled trial (RCT) TUBA was aimed to strengthen adolescents' autonomy and self-management and it was designed by health professionals at centre of Adolescent Medicine, Rigshospitalet, Denmark. The aim and design of the study were discussed with adolescents with rheumatological illness in a workshop, who were invited from the organisation The Society for Adolescents with Arthritis. The TUBA participants were recruited from the Department of Paediatric Rheumatology at Rigshospitalet from March 2013. The inclusion criteria were adolescents 12–20 years of age with a definite diagnosis of JIA with either systemic onset, oligo articular, polyarticular, enthesitis-related or psoriatic who were being treated with disease-modifying medication, e.g. methotrexate or biological agents. Exclusion criteria were adolescents with severe cognitive disorders and patients who did not speak Danish. In March 2016, 116 adolescents with JIA were randomised, 64 as interventions and 52 as controls. One hundred and twenty declined to participate and 12 dropped out of the study (Figure 1). Results from the TUBA intervention will be published elsewhere.

The adolescents, who were randomised to the intervention group, were offered two annual consultations in the TUBA transition clinic during a period of 3 years (the first of these consultations took place in August 2013). The TUBA consultations were conducted in parallel with, and as a supplement to, their usual outpatient clinical visits. The adolescent control group were not offered these youth transition consultations, and they continued with their usual outpatient clinical visits. In the outpatient clinic a systematic youth friendly approach was not implemented and the adolescents were usually not seen without parents. However, continuity was prioritised and most adolescents were followed by the same doctor during childhood and adolescence.

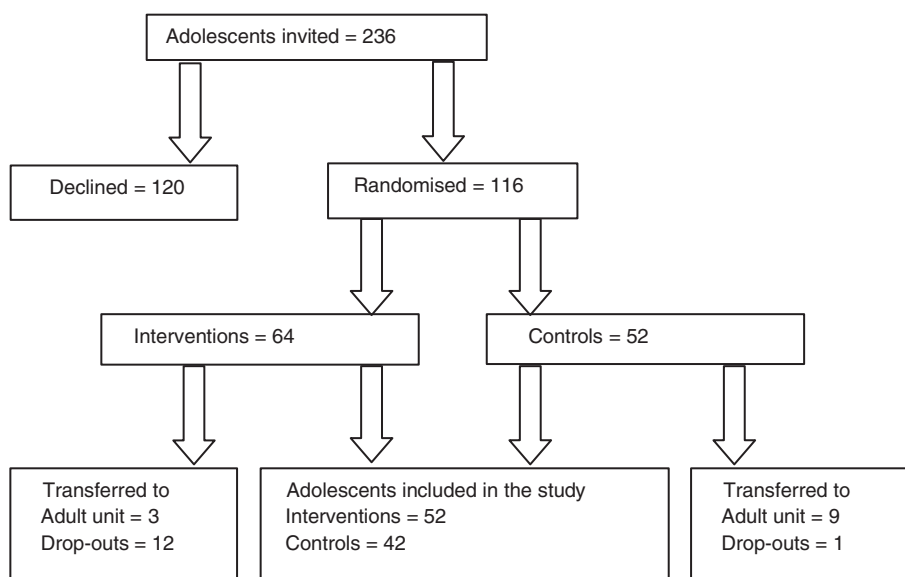


Figure 1: Participants in the study.

We sent an introductory letter to all eligible patients and their parents and a reminder letter 1 week before their usual outpatient clinical visit. The invitation outlined that: (a) the aim of the project was to help adolescents go through the transition from child to adult with a chronic disease; (b) the programme involved two annual visits additional to the usual visits; (c) routine split visits with the opportunity for parents to participate in the last part of the visit; (d) typical topics that would usually be addressed during the consultations (e.g. school, friends, boy/girlfriends and intimacy, alcohol and tobacco), as well as any issues the adolescents wanted to address; (e) the opportunity to meet other adolescents with JIA in groups, if they wished to. Furthermore, the letter described the project background with the following wording: ‘(During adolescence) you have to find out “who am I?”, how to care for school and friends, how to establish independence from your parents and how to take more responsibility for your life, illness and treatment. Many adolescents start to think more about the disease, what it means for everyday life and the future. It can be difficult to make your life fit around treatment plans and visits to the hospital’. This information was also given orally to each adolescent by members of the research group (KAB, SH or the two project nurses) in a secluded room to ensure confidentiality. The information covered topics of conversation and the aim of the project, as well as answering questions from the adolescents and their parents.

Adolescents recruited for the intervention met a doctor and a nurse (always the same pair) trained in adolescent medicine (18) and in motivational interviewing (19), using the structured youth screening tool HEADSS (20). At the TUBA transition clinic, the adolescents were offered: 60 min split-visit consultations with the participation of parents in the latter part, afternoon consultations (2 pm to 6 pm), oral and written information regarding confidentiality and informed consent, and a brief patient education session (discussing diagnosis, prognosis, treatment, treatment adherence and medicine administration and cheque for the adolescent’s need for more information). The effect of the TUBA intervention was measured as adherence to medication (MMAS-8) (primary outcome), patient experience (Mind the Gap) and quality of life (pedSQL 4.0 and JAMAR).

The study protocol was approved by the Ethics Committee (H-4-2012-142) and by the Danish Data Protection Agency (2007-58-0015 and 30-1197). Written informed consent was obtained from all adolescents and from parents of adolescents under 18 years of age.

Feasibility study

This feasibility study consisted of calculation analyses of reasons for declining, and reasons for dropping out of the intervention, as well as qualitative analyses using focus group interviews and follow-up telephone interviews of the advantages and disadvantages of participating and reasons for no-shows.

Data collection

Data for the analysis of reasons for declining to participate were collected between March 2013 and March 2016. Adolescents who declined to participate in TUBA were asked the reason why at the time of recruitment to the project. Data were collected and written

down while the patients were questioned in a secluded room outside the Paediatric Rheumatological Clinic. Drop-out data were collected by SH and KAB together with two project nurses continuously between August 2013 and March 2016 as the patients dropped out. Data regarding advantages, disadvantages and reasons for no-shows were collected by SH through focus group interviews between May and October 2014 and through follow-up telephone interviews in August 2015.

Setting and participants in the qualitative analysis

A purposive sampling technique was used to recruit participants to the focus groups. All participants included in the intervention group before October 2014 were invited by a personal letter (the focus group interviews were both aimed to evaluate the TUBA intervention through this feasibility study and to explore identity constructions through another study). SH contacted the participants by telephone 1 week after receiving the letter. Fourteen adolescents aged 12–20 (11 female, three male) responded positively to the invitation, and they were divided into four focus groups. The focus group participants were interviewed from a thematic semi-structured interview guide, which contained questions covering first impressions of TUBA. Data saturation was reached after three focus group interviews (21), but as the last focus group interview had already been planned, it was still conducted. The focus group interviews took place in privacy in a youth café at Rigshospitalet, they were audio-recorded and transcribed verbatim.

The focus group participants were contacted by phone with follow-up questions covering their second impression of TUBA including expectations, experience of no-shows and practical issues. The telephone follow-up interviews were audio-recorded and transcribed verbatim (22). Quotes for use in this article were subsequently translated into English.

When the focus group interviews were held, the 14 participants had attended one to two TUBA consultations each, and none of them had any no-shows. At the follow-up telephone interviews the 14 participants had attended up to four TUBA consultations each and at this time four of them had one or more no-shows, eight had attended all appointments and two participants only had one TUBA consultation before transferring to adult rheumatology and thus could not reflect on a second impression of TUBA. Therefore they were not contacted by telephone with follow-up questions.

Data analysis

The reasons for declining and reasons for dropping out were grouped and calculated by SH and KAB. The qualitative part was analysed using a thematic analysis approach according to Braun and Clarke (23). The analysis process involved identifying, coding and categorising themes across data. SH did the initial coding subsequently discussed themes across the data with BHH, KAB and KS to reach an agreement on the final coding. Rigour to ensure dependability and credibility of the study was established by properly transcribing data, covering all the main points in the analysis, discussing the findings in the research group and by validating the design. To validate the design, interview guides ensured that the participants were asked the same range of questions (one guide for the focus groups

and one for the telephone follow-up). Furthermore, the participants were asked whether their answers were correctly understood during the interviews (21).

Results

Reasons for declining

The single most common reason for declining was an unspecified 'do not like to participate' (n=22). The vast majority of the adolescents who declined to participate in TUBA mentioned one of several practical reasons including not having time (n=13), distance from home (n=12), and prioritising school (n=12). Also many adolescents could not tolerate any more visits to hospital (n=16), or did not want to participate in any more studies (n=4). Some adolescents argued that the disease should not take charge over their lives (n=7). Also some adolescents succumbed to their parents' decision, and even though some of the adolescents indicated interest in the study, their parents declined (n=7) (Table 1).

Reasons for dropping out

Twelve adolescents dropped out of TUBA from August 2013 to March 2016. Six of them did not specify any reason for dropping out other than 'do not wish to continue'. Two patients moved to another place too far away from the hospital and two patients no longer had any JIA symptoms and anticipated that their treatment in hospital would cease in the near future. One patient did not want any more focus on the illness and one patient did not give a reason for dropping out.

Advantages, disadvantages and reasons for no-shows

The following themes emerged when analysing the focus group interviews and the follow-up telephone interviews. Themes are presented based on each focus area:

1. Advantages: Participating without parents, Trust and confidentiality, Being able to set the agenda, Responsiveness
2. Disadvantages: Unclear aim of the study, Meeting others with JIA, Too few conversations, Transport issues
3. Reasons for no-shows: Forgetting, Being too busy

Table 1: Reasons for declining.

Reasons for declining	Number	%
Do not like to	22	16.8
Do not want more hospital visits	16	12.2
Do not have time	13	9.9
Distance from home	12	9.2
Prioritises school	12	9.2
Parents decline	7	5.3
Do not want the disease to take over	7	5.3
Feel well	6	4.6
Have moved to another place	6	4.6
Do not want to participate in more studies	4	3.1
No joint symptoms	4	3.1
Experience of no need	3	2.3
Too much else to think about	2	1.5
Too ill	2	1.5
Other reasons	6	4.6
No reason specified	9	6.9
Total	131	100.0

One hundred and twenty adolescents declined to participate in TUBA. Nine adolescents gave two reasons for not participating, and one adolescent gave three reasons for not participating (131 reasons). The category 'Other reasons' consists of specific reasons presented only one time each by six adolescents: (1) Too young (2) too independent (3) too shy to participate without parents (4) the consultation is too personal (5) in control of my life (6) know all about my illness.

Advantages

Participating without parents

Some of the adolescents and their parents had either forgotten or had not read the information material explaining that the first part of the consultation was with the adolescent alone. Therefore some parents routinely went into the consulting room and sat down next to their child and did not leave the room on their own initiative. As a consequence, the doctor had to give the parents a more thorough explanation about the split-visit model and ask them to wait outside. One girl was surprised when she realised that she was going to talk to the doctor and nurse without her mother:

'I thought that my parents would be at the conversation, so I was a bit shocked that they weren't. I didn't know that until I got to the consultation, but it was fine that they weren't there' (girl, 12 years).

Many of the adolescents expressed satisfaction with participating without their parents; none of them said that they did not like being without their parents, and some (most of the older adolescents) even took it for granted,

because they had attended outpatient visits without their parents before.

Trust and confidentiality

The doctor and the nurse were perceived as ‘real’ people, who were genuinely interested in the adolescents; they were considered as more than just health professionals. All participants in the focus groups indicated that they greatly appreciated the trust which arose between them and the doctor and nurse. Some even felt confidentiality in the same moment they entered the conversation room:

‘She (the nurse) came in and very quickly became my friend, if I can put it like that [...] instead of saying “I’m a nurse and I’m going to ask you a lot of medical questions”, she came in and we sat and had a proper chat, like two friends’ (girl, 19 years).

The adolescents felt that the doctor and the nurse spoke to them as equals and they never felt that they were spoken to as minors. Some of the adolescents said that they could not figure out who was the doctor and who was the nurse, because the talk time was equally divided between them and they asked the same types of questions, which was not “doctor like” and because they did not wear white coats. The adolescents explained that the questions were very personal and they needed to be confident with the doctor and the nurse to answer them. They appreciated that the doctor and nurse raised personal issues, because it often feels so difficult to do so yourself in that situation. Several adolescents felt that not having previously known the doctor and the nurse made it easier to talk about difficult issues. Some of the adolescents appreciated being able to speak freely without their parents listening. One adolescent explained that the doctor and nurse ‘hit the nail on the head’, meaning that they asked her exactly about the things in life that occupied her thoughts the most. The doctor and nurse created a room of familiarity, where the adolescents could talk about things that they would not tell their parents for fear of worrying them.

Being able to set the agenda

One of the aspects that made the adolescents satisfied with the consultations, was being able to get answers to all their questions, and being able to ask about things, which they thought were unconnected with their illness. One girl was grateful about being able to discuss what would happen in the transfer from the children’s to the adults’ unit:

‘I usually ask a lot of questions about what will happen in the future, I’ve always been very confused about that. And I actually think the consultations are really great in the way that I think about some things, some important things, such as consequences or what will happen in the future in general, which maybe I wouldn’t otherwise do, and they give me some proper answers’ (girl, 16 years).

Most adolescents appreciated having the opportunity to set the agenda for the conversation, and that they had to think about how to answer and formulate their responses, as their parents were not in the room to assist. One of the adolescents said that the consultations made her look at her life with JIA ‘from a different angle’, because she herself was allowed to address issues that concerned her.

Responsiveness

All adolescents experienced a great responsiveness from the doctor and nurse and some mentioned ‘responsiveness’ as their main reason for attending the consultations. The adolescents felt understood and some of them also appreciated advice on topics that concerned them. They noted that there had been plenty of time, so they felt that the doctor and nurse prioritised meeting them. Most adolescents appreciated that the doctor and nurse showed interest in them as a whole person. One girl explained:

‘Arthritis is a part of me, I mean, it’s a part of the person, and everything gets tangled together [...] and the most brilliant question they asked me was “who are you?” because I’ve never been asked that before [...] yes, they just wanted to know who I was and why I did the things and all that, I’ve never been asked that “who are you?”’ (girl, 13 years).

The conversation gave the adolescents an opportunity to reflect on their illness as well as their adolescent development and how these related to identity.

Disadvantages

Unclear aim of the study

Many of the adolescents did not know the aim of TUBA, either before or after their first consultation. Before the first visit most adolescents had no expectations of what would happen in the consultations or how the talks would benefit them. They said that it was hard to imagine what was going to happen:

'I didn't actually have any expectations about it, because I thought it was a bit hard to think about, so I thought I'd just try and see how it was' (girl, 17 years).

Furthermore, after participating in the consultations, several adolescents were uncertain about the objective of the consultations. Most adolescents had difficulty realising that TUBA supported the development of autonomy and independence toward transfer to the adult department. Only one adolescent was aware that taking part in the consultations without parents was a way of strengthening her autonomy:

'[The consultations are preparing me for transfer] in the sense that I'm alone in there and it's me who's doing the talking and explaining how I feel and how I see my illness' (girl, 17 years).

Meeting others with JIA

Several of the adolescents took note of the description of the possibility of meeting other adolescents with JIA in groups. This was described in the introduction letter that was sent prior to recruitment. However, none of the interviewed adolescents were interested in participating in groups, and they were relieved when they discovered that they were not forced to meet others:

'I actually thought it would be some sort of "sitting in a circle" and trying to chat with some people my age and I thought that sort of thing was bullshit. But it wasn't like that at all' (girl, 18 years).

Too few conversations

Most of the focus group participants felt that two annual consultations in TUBA were plenty. However, some of them thought that the consultations were held too infrequently, because they had difficulty remembering what they had talked about it in the previous consultation. To compensate for this, it was possible to book in extra consultations, which some of the adolescents did because the conversations helped them through a difficult period of life, e.g. in school.

Transport issues

Transportation to and from hospital was perceived as a barrier and some of the participants described the transport as 'time-consuming', 'a challenge' and 'travelling times are hard to fit together'. However, they all prioritised

coming. Many were dependent on their parents for transportation to the hospital.

Reasons for no-shows

Forgetting

Some of the participants explained that they were not quite sure if they had forgotten an appointment in TUBA. Most of them had many different appointments and they told that they could easily fail to attend some of them. However, one adolescent knew for sure that she had forgotten an appointment, as she had forgotten to put it on her calendar. Another adolescent explained that she forgot the appointment because she was engrossed by exams and the appointment popped into her head a long time after.

Being busy

Two adolescents told that they were too busy with exams and "other things" to attend appointments in TUBA. They both knew that they had failed to come and that they had not cancelled the appointment in advance even though they knew that the doctor and the nurse were waiting for them in the consultation.

Discussion

More than half of the eligible adolescents declined to participate in the transition intervention. The vast majority of the adolescents indicated practical reasons for not participating in TUBA. Some adolescents also indicated that they did not want to talk about the disease anymore, because they did not want the disease to take over their lives, because they felt well, or because they had already spent too much time on hospital visits. The adolescents' focus on disease in their reasons for declining to participate suggests that they only had a vague picture of what TUBA was about. The reasons might be found in the health professionals' difficulties when explaining the aim of the project orally as well as in the written information. Even some of the participants included in TUBA had difficulties seeing the purpose of the consultations. However, even though most adolescents were not aware that TUBA was aimed to strengthen self-management and autonomy in the transition to adulthood, including transfer to the adult rheumatology

department, some of them said that they received answers to their questions about the future and that participating without parents prepared them for future consultations with health professionals. The adolescents were not aware that the doctor's and nurse's way of communicating were a way of preparing them for future relationships to health professionals. However, in line with other studies, the adolescents were thrilled with this method of welcoming them, as well as with the confidentiality and trust that arose in the communication (24). The adolescents also appreciated the talk about identity, e.g. 'Who am I?', and responsibility for their life and future. These themes are in line with a study on identity constructions in adolescents with chronic illness during transition (25).

The reasons for declining to participate are in some points similar to refusals in a study of adolescents with spina bifida, who were recruited to a transition programme (26). Seven percent found it too time consuming to participate and 19% were just not interested. However, in that study the most common reason for declining was 'shy/embarrassed/unable'. In our study, only one adolescent used the argument 'too shy to participate'. In line with a study on asthma, parents sometimes declined participation on their child's behalf (27). Studies on experiences of benefits of and barriers against participating in a transition programme among adolescents with chronic illness are sparse. However, our study is in line with one of the findings in a study of adolescents with congenital heart disease, which showed that adolescents sometimes found attending the consultations without their parents unexpected (6). The unexpectedness may be anticipated by targeting communication to younger children in an age and developmentally appropriate manner as early as possible before transition starts to prepare both adolescents and their parents for transition with growing competency and independence. In line with our study, a study on young adults with chronic kidney disease found that a welcoming environment motivated the patients to attend (28). The problem with patients declining to participate in TUBA is well known among RCT studies. In a review of 114 trials in the UK, only one third achieved their original recruitment target and 63% had early recruitment problems (15). The problem with no-shows in TUBA is in line with a review on young patients' no-shows in health care; those aged 17–40 years had a greater proportion of no-shows than other age groups and young people aged 0–40 years accounted for 68% of all no-shows (16). A study of adolescent's no-shows in an outpatient clinic gave similar results (17).

Some limitations of our study should be taken into consideration. Although several guidelines exist (9–14), we still lack knowledge about which elements in transition

programmes are effective. Thus, the TUBA intervention must be seen as a contribution to the research field – one way to intervene during transition. This means that the results cannot be generalised to transition programmes using other methods. As the adolescents always met the same doctor and nurse it might also be difficult to know whether we had tested the feasibility of the method used or the health professionals involved. Also, the health care setting might not be transferable. Seventeen percentage of the adolescents who declined to participate in the study did not specify any other reason than 'do not like to participate' and 50% of the adolescents who dropped out did not specify any other reason than 'do not wish to continue'. To deepen the insight into the reasons why qualitative interviews with these adolescents could have strengthened the study.

When designing a future transition programme we will argue for the integration of the two annual transition conversations into the mandatory consultations with the medical specialist. It would be advantageous to hold the conversations in continuation of the consultation, with participation of a transition specialist/coordinator (if the medical specialist is not trained in adolescent medicine). Integration of transition conversations into the mandatory consultations will probably minimise no-shows, and level of declining to participate, as adolescents do not have to show up for extra consultations. Also talking about adolescence related issues rather than illness should be a high priority in future transition programmes. Whether groups for adolescents should be part of a transition programme could be debated as the participants in our study found it a disadvantage of the intervention. One of the TUBA project's challenges was that internationally recommended issues related to transition, e.g. having a transition manager, coordination between paediatric and adult professionals, making a transition plan and making treatment plans (9–14), were not possible under the auspices of the intervention. Future transition programmes may benefit from individually organised programmes according to adolescent patients' preferences and needs allowing selection of elements from a full transition package. Such tailoring can clarify motivations thus facilitate participation and reduce drop-out rates and no-shows.

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