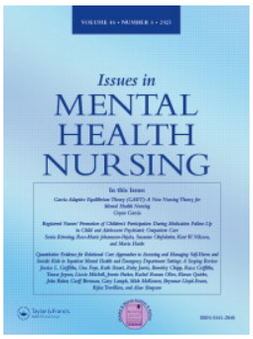

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Registered Nurses' Promotion of Children's Participation During Medication Follow-Up in Child and Adolescent Psychiatric Outpatient Care

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ABSTRACT

Children treated with psychotropic medication have regular medication follow-ups with registered nurses (RNs) at the child and adolescent psychiatric outpatient care (CAPOC) unit, where RNs are responsible for ensuring that children can actively participate in their care on their own terms. This study explored how RNs in Swedish CAPOC units promote children's participation in medication follow-ups. Five focus group interviews were conducted with in total 32 RNs, and the data obtained were analyzed by qualitative thematic analysis. Three themes demonstrate how RNs adapt the medication follow-ups to promote children's participation: the first concerns balancing the needs and desires of both the child and the parents; the second involves recognizing each child based on their unique circumstances and interests; and the third theme is about how RNs adjust their communication to ensure that the child is given comprehensible information and has the opportunity to express themself. Our findings highlight how RNs promote children's participation in medication follow-ups and the challenges they encounter in accordance with child-centered care. In this three-way relationship with RNs, the child, and parents, RNs need to balance between the child's perspective and the parents' needs and desires.

Introduction

Children have the right to participate in all situations of their concern (SFS, 2017; United Nations Children's Fund, 2024) and a child's participation in care situations is a key element of child-centered care. Participation elevates the child's central place and is not only about being part of the care situation but is also about actively participating in it (Carlström et al., 2021), for example, when the child is to be included during their medication follow-up. Such situations occur in the Swedish child and adolescent psychiatric outpatient care (CAPOC), where children up to 18 years receive mental health care. All children who come to the CAPOC unit for medication follow-up by a registered nurse (RN) suffer from mental illness, and the functional impairment it can imply for children (Wille et al., 2008) may contribute to difficulties regarding their participation during medication follow-ups.

Mental illness can be described as a disturbance in the individual's behavior, emotional regulation, or cognition and often leads to impairment or distress (World Health Organization, 2024). Globally, 14% of all children aged 10–19 years suffer from mental illness (World Health Organization, 2022). In Sweden, the prevalence of mental illness in children under 18 years of age is increasing and has doubled since the 1980s (Public Health Agency of Sweden (Folkhalsomyndigheten), 2018), and today 12% of all girls and 13% of all boys between 10 and 17 years receives care for mental health problems (National Board of Health and Welfare, 2024).

International research shows an increase in the number of children being prescribed with psychopharmaceuticals (Altuwairqi, 2024; Bor et al., 2014; Murphy & Fonagy, 2012) especially during and after the COVID-19 pandemic (Bitsko et al., 2022; Hardie et al., 2023). In Sweden, the increase in mental illness among children has led to a rise in the need for psychiatric care and treatment with psychotropic medication (National Board of Health and Welfare, 2020). Therefore, medication follow-ups at the CAPOC unit need to be systematic and evidence-based to follow the children's health over time and ensure that they receive adequate and safe care. In addition, children need to be included in follow-ups on their own terms, which implies their active participation (Greenhill et al., 2003; Solmi et al., 2020). Children's experiences of participation may affect their well-being, function, and their opportunities for development (Axelsson et al., 2022; Koelch & Fegert, 2010). A child-centered approach based on the child's narrative and a partnership with the child and their parents may facilitate and promote children's

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participation in their medication follow-ups with RNs (Coyne et al., 2018).

In the Swedish CAPOC unit, RNs have the responsibility for regular medication follow-ups, that is, to care for children being treated with psychotropic medication and to support them and their parents. During the medication follow-up, the RN asks questions about the child's mental illness and effects, including side effects of the medication in accordance with the current national care program. RNs also take measurements to assess the child's state of physical health because of the risks to children who medicate with psychoactive substances (Graham et al., 2011). Adherence to a child's medication is dependent on the child participating in planning the medication treatment (Gardiner & Dvorkin, 2006). Poor adherence can also negatively affect the relationship between the RN and the patient (Gardiner & Dvorkin, 2006; Osterberg & Blaschke, 2005) and in turn affect the child's participation. In these medication follow-ups, it is important to gain access to the child's narrative because a child's perspective only according to the RN's perspective of the child is not sufficient. The child's perspective on the situation is necessary to develop a partnership with the child (Lindahl et al., 2021; Söderbäck et al., 2011; Sommer et al., 2013). Furthermore, this partnership needs to be based on trust and respect to contribute to the child's experience of participation (Biering, 2010; Moreno-Poyato et al., 2016; O'Connor et al., 2021, Persson et al., 2017 Quaye et al., 2019).

Previous research shows that children in psychiatric care often lack trust in their caregivers, which may limit their opportunities to participate in their care (Biering, 2010; Nolkemper et al., 2019; Persson et al., 2017). Moreover, children may experience that they are not involved in decisions or even informed about the plan for their future care (Persson et al., 2017).

Given the lack of knowledge about how RNs in the CAPOC unit promote children's participation, there is a need for research on this important issue. Accordingly, the specific objective of this study was to explore how RNs in a Swedish CAPOC unit promote children's participation in medication follow-ups.

Materials and methods

Design

A qualitative design with inductive approach was used with focus group interviews as data collection (Krueger & Casey, 2014).

Participants and recruitment

The participants were RNs working in outpatient psychiatric care for children and adolescents. The sample was strategically selected as described by Krueger and Casey (2014) in an attempt to include nurses specialized in psychiatric care with at least one year of experience of working in a CAPOC unit. However, given the national shortage and high turnover of specialized nurses, the inclusion criteria were changed to apply to all registered nurses who were working or had worked with medication follow-ups, regardless of how long. Recruitment was carried out by verbal and written requests to nine CAPOC units in three regions of Sweden. In total, 32 RNs were included in the study (30 women, 2 men). Of the 32 participants, 29 conducted medication follow-ups in their daily work and the remaining three had previously worked with medication follow-ups but currently had other tasks or other positions. Participants were aged 32–70 years (average, 47 years), with an average of 17 years experience working as an RN, and an average of 4.8 years working in a CAPOC unit. 20 participants were specialists in different areas and 13 of the participants had studied additional courses.

Data collection

An interview guide was developed based on Krueger and Casey (2014), moving from general to specific questions (Table 1). Five focus group interviews were conducted with RNs between October 2022 and February 2023. Each focus group comprised 5–8 participants and lasted 60–90 min. The interviews were audio recorded and took place at the RNs' workplace. Most of the RNs participated in face-to-face interviews but six participated online as they worked from other locations. All focus group interviews were conducted by a moderator (SR) accompanied by an assistant moderator (RMJP). The recordings were transcribed verbatim by the first author and checked for accuracy by the assistant moderator.

Data analysis

The interviews were analyzed using an inductive approach to reflexive thematic analysis as described by Braun and Clarke (2006), which allows for flexibility in the sense that the content is not adapted to existing theory. The analysis was conducted through six phases while moving back and

Table 1. Interview Guide.

Opening question
1. Please tell us your name and where you work.
Introductory question:
2. Please describe your work as a RN in CAPOC.
Transition questions
3. Please describe your thoughts/views on the concept of participation in health care in general.
4. Please describe what participation means for children and parents in CAPOC.
Key questions
5. Please describe the children's participation in medication follow-ups at CAPOC.
a. Follow-ups?
b. How can the children's participation in medication follow-ups be promoted?
6. Please describe the parents' participation in medication follow-ups at CAPOC.
a. What are the obstacles and prerequisites for the parents' participation in their children's medication follow ups?
b. How can the parent's participation in medication follow-ups be promoted?
Probing questions: Can you give an example? Could you explain further? What do you mean?
Final question
• The assistant moderator was invited to pose probing/clarifying questions.
• Based on the aim of this interview and today's discussion, is there anything you would like to add?

forth between the phases, which can lead to new interpretations and understanding (Braun & Clarke, 2021; Byrne, 2022). In the initial phase, *familiarization with the data*, the transcribed material was repeatedly read and compared with the recordings and the notes taken by the assistant moderator to reduce the risk of errors and missing information. In the second phase, *generating initial codes*, sentences were picked out in the collected data that responded to the study aims, and initial codes were identified. In the third phase, *searching for themes*, the themes and subthemes emerged. In the fourth phase, *reviewing themes*, the codes and themes where reworked and refined by looking for coherent patterns in each theme. Some themes collapsed and some further themes emerged. In the fifth phase *defining and naming the themes*, the themes were processed and named. The authors' analysis of the collected data evolved throughout these processes, and identification codes and themes changed in accordance with the thematic analysis. When the analysis was complete, with the last phase, *producing the report*, the text began to take shape and quotes from the transcribed material were inserted into the text to substantiate the interviews. To confirm the findings, one of the transcripts was randomly selected and independently analyzed by the assistant moderator (RMJP). Interpretations were discussed by the authors until consensus was reached to reduce the influence of personal interpretations and bias.

Ethical approval

All study participants were informed beforehand of their right to decline participation and to withdraw their participation at any time. All study participants received both oral and written information about the study and have given consent to participate. The study (2022-03268-01; 2022-04892-02) was approved by the Swedish Ethical Review Authority and conducted in accordance with the principles stated in the World medical association Declaration of Helsinki.

Results

We highlight three themes that reflect how RNs promote children's participation during medication follow-ups at the CAPOC unit. The first theme, *to balance between the child and parents*, reflects how RNs adapt the medication follow-up to take both the child's and the parents' needs and wishes into account. The second theme, *to recognize each child*, shows how RNs adapt the medication follow-up based on the child's unique circumstances and interests. The third theme, *to adjust one's communication*, involves RNs adapting their communication during the medication follow-up to ensure that the child is given comprehensible information and has the opportunity to express themself.

To balance between the child and parents

RNs describe how their promotion of children's participation during medication follow-ups implies the need to balance both the child's and the parents' perceptions of the child's mental health problems. Parents may have conflicting perceptions about their child's everyday functioning and medication.

RNs comment that balancing actions are necessary because parents may jeopardize the child's opportunity to take part in medication follow-ups by not accompanying them to the appointments or by not including them in online follow-ups. In addition, parents may affect their child's participation by having a negative attitude toward their child, instead prioritizing their own agenda or having opinions on the topics that RNs should discuss with the child. Some parents can even tell their child that what they are experiencing is wrong, and some are not involved in the child's medical treatment at all. In such encounters, RNs note that they address the child's considerations first in a direct way to show that the child is the main person during the medication follow-up. Furthermore, they may ask the parents to wait outside, interrupt the parents, or invite the child to speak instead when the parents focus on problem issues, such as school or other everyday activities and relationships. Furthermore, RNs describe their efforts to balance between the child and parents during the medication follow-up include situations in which the child has difficulties expressing themself in front of their parents about, for example, feeling different from other children or existential thoughts. In such situations, RNs provide space for the child by taking them aside, by going to another room to conduct an examination such as measuring their blood pressure, or by taking them for a walk around the building. How RNs provide space for the child is shown by the following quote.

> You go with the child alone to another room to take measurements. You get the opportunity to check with the child how things are at home or if there is something they want to talk about without mom or dad joining in. (FG.3)

Nevertheless, there are always children who want their parents to act on their behalf. The parents are therefore acknowledged as an important resource to promote the child's participation during medication follow-up. RNs indicate that parents can be key to the child's participation as they may provide an overall picture of the child's situation and help the child to express themself during medication follow-up by nodding their head or raising their eyebrows if they agree or disagree with what their child says. RNs also stress the importance of parents discussing the child's condition with the child before the visit to the CAPOC unit to identify what needs to be addressed during the medication follow-up.

RNs also describe the urge to consider the parents' perceptions, their needs for support, and expectations to avoid parents becoming an obstacle to the child's participation. RNs note how parents may have unrealistic expectations that the medication treatment will solve all the child's problems and expect that their child will be able to manage matters the same as other children. Parents may also have made up their mind about the treatment they want for their child and are not open to other solutions. In that case, RNs need to support the parents in their understanding of the child's

mental illness because it may be difficult for them to grasp their child's situation due to fear or cultural issues. RNs also try to sense when the child or the parents need to talk privately, considering that both parties are vulnerable in such situations.

> That's the challenge … You're not just working with the child, you're getting the whole family package as well, and everyone must somehow feel a little seen and validated during the visit. (FG.2)

For RNs, various issues may hinder their actions to create this balance between the child and the parents, such as when there are conflicts in the family and parents do not communicate well with each other. In these situations, RNs need to mediate to improve collaboration without offending parents or the child because prolonged conflict between them may end up with the child refusing to attend the medication follow-up. RNs must balance the situation by showing that they are available without prejudice to manage the visit and find solutions that are acceptable to both the child and their parents. RNs can experience this task as extremely challenging. They also note that it is sometimes better to separate the medication follow-ups, meaning that the child and their parents visit the CAPOC unit separately.

> If anything, that is participation … to listen to both caretakers, the child with one caretaker, the child with the other caretaker and to the child by itself. Then we have hit the spot regarding participation. Then … if we also try to understand the different perspectives. (FG.4)

Importantly, even if visits are conducted separately, the dialogue between the RN, the child, and parents needs to be open.

To recognize each child

RNs try to promote the child's participation by recognizing each individual child. Such recognition is necessary at each encounter because participation in medication follow-ups differs from child to child depending on the child's skills and willingness to participate. RNs make an effort to recognize each child as a person, finding out about their interests and determining specific prerequisites according to the age and stage of development of the child as well as their state of mental illness. This recognition is necessary to show the child respect and allow them to have control in the situation. They may be sad, they may have hurt themself, or are reluctant and afraid to come for medication follow-ups. Furthermore, the child may lack trust in adults, having experienced being let down by adults or having lived in several foster care homes. Some RNs even describe cases where children did not even know that they were on medication, or where the child was forced to attend the medication follow-up by their parents.

> It is important to be clear with the child, to ask, what is it that we can do better to make you want to come? … they say that "no, I don't want to be here" … that you try to develop … what can I do then … to make you want to come here? (FG.1)

RNs further recognize the child by talking about expectations and fears, confirming their feelings, and exploring how they can facilitate the situation without creating pressure. This approach toward the child by identifying them as the central person ensures that they become secure and comfortable to express themselves during the medication follow-up. By involving the child, it makes the follow-up interesting for them and may promote their sense of participation. RNs highlight the importance of constructing reasonable goals for a care plan together with the child, such as improved functions regarding school or sleep. The following quote shows the importance of individualized plans for each child.

> You make individual assessments and … individual plans based on what the problem is. For some, it may be enough to follow them for six months because they are stable. Others may need to be monitored every two weeks because they are unstable. (FG.3)

The next time the child comes for the medication follow-up, the child and the RN can together evaluate the plan. Further recognition comes from allowing the child's voice to be heard in the meeting by documenting the care plan in the child's own words.

Unfortunately, RNs also describe how their workload, a lack of time, and greater use of online follow-ups sometimes prevent them from being able to adequately recognize the child; the child's opportunity to participate is thereby undermined.

To adjust one's communication

RNs are aware of how they adjust their communication to promote the child's participation. Such adjustment includes having an open dialogue about information and treatment expectations based on the child's age and maturity, being aware of their language to provide comprehensible information, listening to the child, and using aids to facilitate the child's ability to express themself and share their perspective on their mental well-being and health. The following quote shows how RNs use pictures to facilitate communication with the child.

> Pictures are part of the children's ability to express themselves when they can't verbally. There are different materials that can be used where the child can really express whether it is something that affects them negatively or positively. And then based on that use the positive as an input. (FG.3)

RNs adjust their communication by first informing the child about the purpose of the follow-up and of their medication; that is, how the medication works and what alternatives there are, as well as what can be expected from the medication.

> If we want it to get better over time, the child must … own their treatment. They need to understand why they medicate … Here is the win, this is the downside … You are making this decision. We are the ones who must help them navigate the factual part … but you make the choice. (FG.4)

This information is then followed by a dialogue about the child's expectations for their medication treatment, the purpose of which is to promote the child's participation in the decision-making process of their medication treatment as well as to protect the child's best interests regarding their health. This approach is used to help the child navigate within the situation and provide hope for the future. RNs adjust their communication based on the child's age and maturity and use pictorial support to provide information and facilitate assessment of their well-being and health.

> I usually use a … scale. That the child or young person can rate their well-being between one and 10 … I usually do that at every … visit … then you can … see …. What number did they estimate at the last visit and then you also see … How is the situation today? (FG.5)

However, RNs caution that because not all information comes across in verbal communication, they also need to listen to what is not being said. They highlight the importance of not drawing their own conclusions based on their own experience. Even if RNs try their best to adjust their communication, the child's opportunity to participate may be jeopardized when a language interpreter is needed in the medication follow-ups when the child and/or the parent/parents do not speak Swedish. In these encounters, the child is committed to, and dependent on, an unknown adult to present their perspective. RNs provide parents with information both verbally and in writing, they invite them to meetings with other caregivers involved with the child if needed like school or social services and give parents the opportunity to participate online or by telephone if they have difficulties joining the child's medication follow-up.

Discussion

The UN Convention on the Rights of the Child (United Nations Children's Fund, 2024) is law in Sweden (SFS, 2017) and claims a child's right to be heard in every situation of their concern, their right to the best health care, and that a child's best interests are considered. In the context of this study, these rights are understood to be the child's right to participation in their own medication follow-up in the CAPOC unit. Our findings show how RNs promote the child's participation by balancing communication between the child and parents, recognizing each child, and adjusting their communication. One way to highlight the child's rights in the CAPOC unit is to understand findings from the perspective of child-centered care, which ensures that a child's needs are met and determines the quality of care for the child (O'Connor et al., 2021; Sumanović-Glamuzina et al., 2013). Furthermore, this approach considers the child's perspective in every aspect of the caring situation and gives the child a voice (Coyne et al., 2018). The concepts of the child's narrative and partnership with the child and their parents are central (Söderbäck et al., 2011) in child-centered care and are the starting point in the following discussion. We argue that medication follow-ups in the CAPOC unit are care situations that need to emanate from a child-centered approach.

Considering the child's narrative requires the health care worker to approach the child from a holistic point of view, where there are opportunities for the child to tell their individual story in their own voice (Coyne et al., 2018). Here, this approach is demonstrated by RNs recognizing each child in the medication follow-up. They listen to the child's narrative by showing an interest in the child as a person. Furthermore, the child's narrative is central when constructing the care plan using the child's own wording. Coyne et al. (2016) argue that the care plan needs to be focused on the child's own preferences and therefore child-centered. Recognizing each child may be understood as the child being listened to irrespective of age, as having their views considered, and being supported in expressing those views. In this way, RNs are able to take the child's perspective into account (Coyne et al., 2018; Söderbäck et al., 2011). In addition, recognizing each child clearly indicates that the child is involved in the decision-making process and shares power and responsibility (Bjønness et al., 2020; Carter et al., 2024; Coyne et al., 2018; Söderbäck et al., 2011). RNs need to recognize each child's unique circumstances and interests, individualize their care, and adapt to each child's ability and willingness to participate. However, to date, there are no clear descriptions of how children take part in the decision-making process.

Although recognizing the child is especially important in a vulnerable population such as children with mental health problems, our findings show that RNs' experience of a high workload, a lack of time, and the demands of routine clinical practice in the CAPOC unit make it difficult for them to achieve this and thus consider the child's narrative. Bjønness et al. (2020) note that in mental health care for adolescents, shared decision-making and participation are possible only when there is flexibility in clinical routines that fit the adolescent. Sometimes the child's participation may conflict with the regulations of the UN Convention on the Rights of the Child (SFS, 2017, p. 1197), for example, when RNs must look after the best interests of the child, but the child does not agree with what is best for themself. RNs had difficulty understanding the child's narrative when the child put themself in a difficult situation, for instance, when they did not want to come for medication follow-ups to monitor the effectiveness of the medication. Söderbäck et al. (2011) stress that it then becomes a challenge for RNs to recognize the child by involving them in decision-making, but at the same time, not expose the child to danger or harm. Coyne et al. (2018) also comment that parents may try to protect their children from decision-making because they feel that the child lacks the necessary competence, which in turn makes participation difficult. Clearly, there is a need for a partnership with the parents to be able to promote participation for the child.

Children do not come on their own for their medication follow-ups in the CAPOC unit. Rather, from a child-centered perspective, the child is part of a three-way partnership with parents and the RN, in which the child is supposed to be the main person, and the adults—the RN and the parents—are supposed to have the child's best interests in mind (Söderbäck et al., 2011). However, our findings show that RNs struggle to fulfill the needs and expectations of both

the child and the parents when, for example, they are required to mediate a conflict between the child and their parents or between the parents.

In the CAPOC unit, the RN and the parents do not always seem to work together in the best interests of the child. This observation is similar to that by Harder et al. (2018), who described a moment in a health care situation where the actions of everyone in the partnership affected the outcome of the situation. Parents sometimes cannot understand the importance of coming to the CAPOC unit for medication follow-ups and the child's medication regime is not followed as carefully as it should be, leading to poor adherence to treatment for the child. Beni Edgcomb and Zima (2018) note that children with severe mental illness are already exposed to poor adherence to treatment, which can be resolved by the RN and the parents working together to promote participation. In the present study, RNs describe how they try to reinforce the concept of the child as the most important person in the medication follow-up by addressing the child first and by sensing when the child needs to talk privately. Nevertheless, as noted, some children do not even know they are on medication or why they are at the CAPOC unit because the parents have not told them. Thus, parents' attitudes and expectations for the child's medication follow-up can affect the child's opportunity to participate. However, RNs need to support the parents in their parental role for them, in turn, to support their child's participation. In a health care situation involving a child, it is necessary for RNs to have a positive relationship with the parents for RNs to have a positive relationship with the child (Harder et al., 2018; Söderbäck et al., 2011). Although the parents are considered the experts on their children and the family dynamic, they still need support from the health care professionals who are the experts on the child's illness (Batchelor & Duke, 2019). Harder et al. (2018) also draw attention to how the partnership between the child and the RN can be affected by the parents' role in the partnership.

Although some parents may not inform their children about their medication and visits to the CAPOC unit, giving information to the child is vital, especially in the case of special needs (Sahlberg et al., 2020). Children with a disability caused by mental illness often have special needs due to their disability and their health situation (Wille et al., 2008). In this study, RNs describe how they adjust their communication during the medication follow-ups to respond to the child's needs. According to the Convention on the Rights of the Child (SFS, 2017, p. 1197), every child has the right to information on equal terms, regardless of whether they have a disability. It is then of vital importance that information given is adapted to each child and their special needs.

Strengths and limitations

A particular strength of this study is that RNs from nine different CAPOC units in three different regions of Sweden were included, which assured rich and varied descriptions of how RNs promote a child's participation during medication follow-ups. Nevertheless, there remains the possibility that additional focus groups could have contributed with additional data to add further nuance. Other strengths were the use of the same moderator in all focus groups and that the questions used as well as the analysis and findings were elaborated upon in the research group.

One potential limitation is that some of the RNs needed to participate online to be able to take part in the study. Such hybrid communication situations may lead to unequal dialogue in the focus group. However, the moderator was aware of this possibility and ensured that those participants had the opportunity to make themselves heard on the same terms as those who participated in person.

Conclusion

This study elucidates how promoting participation in medication follow-ups in children with mental illness is a considerable challenge because it requires RNs to balance the child's perspective and their best interests in promoting the child's rights, health, and well-being and at the same time consider the parents' needs and desires. This three-way relationship implies a complex situation for RNs to handle. Further research on these issues is needed from both children's and parents' perspectives.

Clinical implications

This study contributes with explicit illustrations of how RNs aim to promote children's participation during medication follow-ups. Our findings may be useful in developing care plans with a child-centered approach in CAPOC units. They also enable a deeper understanding of the introduction of medication follow-ups for new employed RNs within CAPOC units, which is an assignment that the RN´s already working at the CAPOC unit are supposed to manage on their own. Importantly, the results reported should contribute to developing clinical routines in accordance with the Convention on the Rights of the Child (SFS, 2017, p. 1197).

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethics statement

Ethical approval was achieved from the Swedish Ethical Review Authority (Dnr: 2022-03268-01;2022-04892-02). Ethical standards for scientific work were followed (WMA, declaration of Helsinki).

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