

BMJ Open “I just wear it and I become normal”: a qualitative study of Tanzanian women’s experiences with long-term vaginal pessary use for stress urinary incontinence

Karina Holm Nissen ¹, Benjamin C Shayo,^{2,3} Vibeke Rasch,^{1,4} Gileard G Masenga,^{2,3} Ditte Søndergaard Linde ^{1,4,5}

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For numbered affiliations see end of article.

Correspondence to

Karina Holm Nissen;
karina_holm_92@hotmail.com

ABSTRACT

Introduction Previous research has shown that vaginal pessaries are a cost-effective treatment for women worldwide suffering from stress urinary incontinence. However, little is known about African women’s experiences with vaginal pessary use. The aim of this study was to understand the experiences of vaginal pessary use among Tanzanian women who had received long-term pessary treatment for stress urinary incontinence.

Methods 15 semi-structured, individual interviews were conducted over a 2-month period in 2019 with Tanzanian women living in the Kilimanjaro Region who suffered from stress urinary incontinence and who had been using a pessary for at least 18 months. The interview transcripts were analysed using qualitative content analysis.

Results The primary motivation for seeking treatment were discomfort from symptoms, social consequences and low quality of life. Perceived benefits from pessary use included improved quality of life with reacquired abilities to perform daily activities, participate in social gatherings, feeling symptom relief and improved sexual relations. Further, some women saw pessary treatment as superior to other locally available treatment options. Perceived barriers for pessary use included shame, husband’s disapproval, limited access to treatment and lack of knowledge among the women as well as healthcare personnel.

Conclusion Vaginal pessaries are well-perceived as a long-term treatment method among Tanzanian women suffering from stress urinary incontinence. This method may have potential to be implemented large scale in Tanzania if combined with basic health education.

INTRODUCTION

Urinary incontinence (UI) is a common gynaecological condition that affects many women worldwide. In low-income countries, the average prevalence of UI is 28.7%.¹ However, in Tanzania the prevalence is even higher, and a recent study found that 42.1% of Tanzanian women suffer from UI.² The

Strengths and limitations of this study

- This is the first African study that elucidates the thoughts, actions and needs among women receiving pessary treatment for stress urinary incontinence.
- The findings indicate that pessaries have both physical and social benefits, however, barriers such as lack of knowledge and shame need to be addressed when implementing pessary treatment.
- The study only includes women with more than 18 months of pessary experience, hence, women with short-term use who have stopped using their pessaries might have different views on pros and cons of pessary use.

high prevalence in resource-limited settings is mainly due to high parity, frequent lifting of heavy objects and limited access to treatment.¹ The higher prevalence in Tanzania may be due to study conditions that provided a safe space to talk about a sensitive issue.² UI is traditionally divided into three types; stress urinary incontinence (SUI), urgency urinary incontinence (UUI) and mixed urinary incontinence (MUI). The most prevalent type is SUI which constitutes approximately 50% of the cases of UI.³ SUI is defined by the International Continence Society as “the complaint of any involuntary loss of urine on effort or physical exertion (eg, sporting activities) or on sneezing or coughing”.⁴ UUI is the complaint of involuntary leakage proceeded by an urgent desire to urinate that is difficult to defer. MUI is when a patient experiences symptoms of both SUI and UUI.

Several studies from high-income countries have shown that UI affect women’s lives in many ways—both physical, social and sexual.^{5–7} Apart from the displeasure of

leaking while coughing, laughing and/or during physical activities, UI may have a number of mental and social consequences including low self-esteem, isolation and abuse.¹ Further, UI may also have a negative impact on women's sexual lives as fear of urinary leakage during coitus may lead to a lower frequency of sexual activities and a general decrease in sexual satisfaction.⁸

A non-invasive, cost-effective treatment of SUI is pessaries.⁹ Studies from high-income countries have shown that pessaries significantly reduce urine leakage among women suffering from SUI.^{10 11} It has previously been documented in the PEDITA (Pelvic floor disorders in Tanzania) study that pessaries are an effective treatment for urine leakage among women suffering from SUI in Tanzania.¹² However, information about long-term experience with pessary treatment is lacking. Further, there are no in-depth data on the women's thoughts and experiences with pessary use.¹² It is important to know if women continue to use their pessaries and what motivates or prevents them from doing so in order to see if pessaries are a feasible long-term treatment for women with SUI in Tanzania. Therefore, a qualitative follow-up study was conducted among participants of the PEDITA study in order to elucidate the thoughts, actions and needs among Tanzanian women, who have received long-term pessary treatment for stress urinary incontinence.

METHODS

Study site and sampling

The study was conducted over a 2-month period in 2019 at two different hospitals in the Kilimanjaro Region, Tanzania. Women were eligible for interviews if they (1) had participated in the PEDITA project, (2) had been diagnosed with SUI, (3) had successfully got fitted with a pessary, (4) had attended the 12 to 18-month follow-up in the PEDITA study and (5) were still using their pessary at the time of the follow-up.

The initial inclusion to the PEDITA project involved awareness campaigns leading to the women voluntarily showing up for questionnaires and examination. If diagnosed with SUI, they were offered an incontinence pessary.¹² During the PEDITA project, 48 women were fitted with an incontinence pessary (figure 1¹³) and followed for 18 months. Thirty-two of these women continued using the pessary beyond 18 months. The study population for the present study involved a subpopulation of 20 out of 32 women who had used the pessary for more than 18 months. The 20 women were purposively sampled according to age and parity and invited by phone (figure 2).

Data collection

Sixteen women (80%) agreed to participate in individual, semi-structured interviews. However, during the interview of one woman it turned out that she had less than 2 weeks of experience with wearing a pessary and she was therefore excluded prior to analysis. The reasons why the four



Figure 1 Picture of a Millex flexible incontinence ring pessary (Millex pessaries, CooperSurgical, Inc).

remaining women were not interviewed were: one woman was excluded as she had her pessary removed at the 18 months follow-up, hence, she was no longer a pessary user, and the other three women agreed to participate when inviting them over the phone but never showed up for the interviews.

The sample size was determined by data saturation as defined by Saunders *et al* and was obtained after 15 interviews.¹⁴

The interviews were conducted by the first author in collaboration with a nurse from the obstetrics and gynaecology department at one of the hospitals. All interviews were conducted in English with the nurse translating simultaneously to Kiswahili and back to English. The nurse had experience with translating qualitative interviews and was informed of the main reasons for doing the interviews prior to their commencement. All interviews took place in a private room at the two different hospitals and all women got their transportation cost refunded.

The interviews lasted 35 min on average (range: 23 to 53 min). The first author, the translating nurse and the participant were the only ones present during the interviews. All interviews were audio recorded and subsequently transcribed *ad verbatim* by two local final-year medical students with experience in transcribing and translating. The transcription process also served as validation of the nurse's translation.

All interviews were guided by a semi-structured interview guide consisting of 22 questions (online supplemental appendix 1). The guide was based on the principles of the Health Belief Model¹⁵ and was inspired by an interview guide from another qualitative study on women's

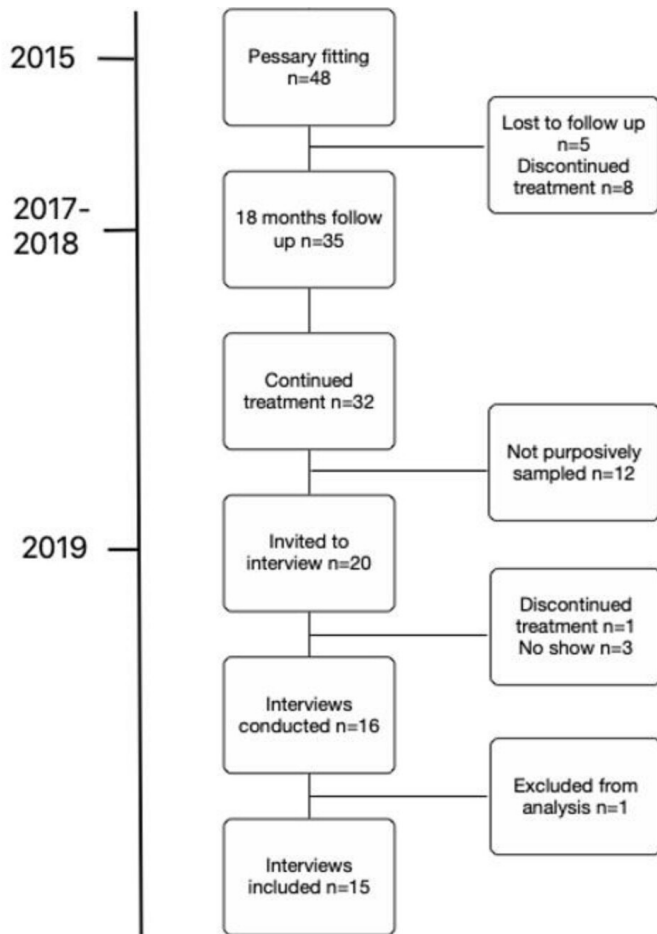


Figure 2 Flowchart and timeline of inclusion from the overall PEDITA (Pelvicfloor disorders in Tanzania) study into the qualitative study.

experience with pessary use.¹⁶ The interview guide was tested in two pilot interviews in the beginning of the data collection period and adjusted slightly according to the experiences made. The pilot interviews were included in the analysis. Sociodemographic characteristics of the women were obtained from the PEDITA files.

The research paradigm that inspired this study was social constructivism, that states that reality is constructed by cultural and social interactions. Therefore, the interactions between participants and researcher generated new knowledge as it was subjectively experienced by the participants.¹⁷

Data analysis

The transcribed interviews were analysed using Qualitative Content Analysis.¹⁸ The data was coded by the use of a coding frame that was created in a deductive-inductive manner. First, elements of the coding frame were deductively based on themes derived from the Health Belief Model¹⁵ and the interview guide (online supplemental appendix 1). Second, the coding frame was applied to the data which was coded according to the deductively created categories. When 20% of the data was coded, the coding frame was reviewed and categories that arose

inductively from the data were added to the coding frame (table 1). NVivo 12 was used for the data analysis and coding process. After the coding process, the interview ID's were replaced by a pseudonym using the top 15 names for Tanzanian women.¹⁹ The study is reported in accordance with the Standards for Reporting Qualitative Research (SRQR) guidelines (online supplemental appendix 2).²⁰

Patient and public involvement

The participants were not involved in designing or recruiting for this study. One participant, who was a nurse at one of the hospitals, assisted in arranging the use of a private room for interviews.

Ethical considerations

Ethical clearance for the overall PEDITA project (certificate number 811) was obtained from the Kilimanjaro Christian Medical University College's Clinical Research Ethical Review Committee on 11 February 2015. A renewal was obtained on 11 February 2019 including an amendment allowing this substudy to take place. An information sheet and informed consent was read aloud to all participating women before the interviews started. All women gave their oral and written consent.

FINDINGS

Characteristics of participants

Demographic information of the women is summarised in table 2. The mean age of the participants were 55.3 years ranging from 45 to 72 years. On average they had 4.9 children ranging from 2 to 7 children.

Motivation

The motivation for seeking pessary treatment and for continued pessary use were discussed during the interviews, and it was clear that the women had different motivations. However, social consequences, symptoms and quality of life were the main reasons why women had joined the PEDITA project and continued using pessaries.

The women in the study painted a picture of life with SUI as a life with suffering and pain. For instance, Janeth described how she “felt like the community had stigmatised me” (Janeth) and Editha explained that “what was bothering me the most was the pain I felt during my activities and the smell of urine throughout the day” (Editha). Alice described it this way,

Due to my condition, I couldn't travel and if I did, I wouldn't take water because I will end up disturbing the driver every time that I want to pee. So, I was happy to get this opportunity as it benefited me. (Alice)

After getting fitted with a pessary the women had different motivations for continued pessary use. For example, Mary, said that “as for now, why would I stop using it when it helps me?” (Mary). Others had more elaborate reasons for continued use,

Table 1 Elements of final coding frame

Primary category	First subcategory	Second subcategory	Third subcategory
Motivation	For seeking treatment	Symptoms	–
		Quality of life	–
	Continued pessary use	Less	Asymptomatic Physician's advice
		Continuously	Symptom relief Physician's advice
Perceived benefits	Quality of life	Daily activities	–
		Sexual relations	–
		Social life	–
		Symptom relief	Pain Leakage
	Superior treatment	Not feeling the pessary	–
		No side effects	–
Perceived barriers	Emotional	Shame	–
		Husband's disapproval	Sexual relations
	External factors	Access	–
		Lack of knowledge	Women Physicians

Table 2 Characteristics of participants

Characteristics	N (%)
Age	
Mean	55.3
Minimum	45
Maximum	72
District	
Hai	8 (53)
Same	3 (20)
Rombo	4 (27)
Marital status	
Married	12 (80)
Divorced	1 (7)
Widow	2 (13)
Sexual activity	
Active	12 (80)
Not active	3 (20)
Number of children	
Mean	4.9
Minimum	2
Maximum	7
Years of pessary use	
Mean	2.9
Minimum	2
Maximum	4

Something that motivated me to use the pessary was because the doctor advised me to use it and also I had some fear that if I won't use [ed. it] the problem might get worse and I normally obey the orders given by doctors so that the problem doesn't get worse. (Neema)

However, not all women proceeded to use their pessary continuously. Their reasons for cutting down on the use were either "because that condition of urine to pass has stopped" (Victoria) or,

I was worried that if I wear it continuously it could cause some other effects. Also, I was curious to know of the improvements [...]. (Neema)

Perceived benefits

In general, the women had a very positive attitude towards pessary use and it was evident that the benefits of pessary use were many. Several women were so positively inclined towards pessary use that they had shared their experience with other women suffering from UI, hoping for them to get the same treatment. For example, Alice explained it this way,

Because the problems I have with urinary incontinence are not always good so I give her advice for her benefit and that she may be cured so she can enjoy her life. (Alice)

Quality of life

All 15 women stated that their quality of life had improved since starting to use a pessary. For example, Glory said that, "I feel good, I have peace" (Glory). The improved quality

of life was attributed to reacquired ability to perform daily activities, participating in social life, feeling symptom relief and being able to enjoy sexual relations. To be able to be around other people and enjoy a busy social life was a benefit many experienced. Perucy explained it this way,

I'm okay, because I wasn't able to mix up with people in the community, because with that problem you can't mix with people, even at the village. I was elected to be a leader and I wasn't able to stay in a meeting with my fellows, [ed. and if] I had to leave, wouldn't they think bad about me? [...] That's why I'm telling you [ed. that] this problem discriminate, but with that device I was able to stay with my fellows normally until the time ends, and I would go to urinate at my own good time. (Perucy)

To some women, an active sexual life was important for their quality of life. While some women removed their pessaries during sex, others enjoyed the freedom of the pessary,

Even when having sex, you don't feel like there is something. (Glory)

Pessaries superior to surgery

None of the 15 women knew of any kind of official treatment for SUI before they joined the PEDITA project. When they were informed that the treatment options for advanced SUI consisted of vaginal pessary or surgery, some had a clear opinion on which was the right choice for them,

It's good [ed. the pessary] because if you explain your problem to the doctors, they can advise you in a simple way compared with an operation. Operation will first disturb you, take your time and it will give you pain. (Victoria)

Others felt it as a therapeutic benefit that they could not feel the device at all,

When I was wearing it, I wasn't feeling like I had something inside me. It has helped me, it's not like using the drugs or being operated for that condition [...]. I just wear it and I become normal. (Glory)

Not all women had the same experience, but they all eventually coped with the pessary,

Probably they [ed. other women] feel the same way I do—that it is not normal—but because it is for treatment purposes, they just accept it. (Brenda)

Perceived barriers

During the interviews the perceived barriers for pessary use were also discussed. Some women had had to overcome barriers themselves. Others could only reflect on what barriers, they would expect other women to face in the process of starting and maintaining pessary treatment.

External factors

One of the biggest challenges for many women in Tanzania is limited access to health services. Glory described how she thought limited access was a barrier for pessary use,

For sure it's good [ed. the pessary] and if these white people [ed. the researchers] could stay here and visit us in our villages it could be better because if you tell a woman to come all the way to here [ed. to the hospital] she will tell you she doesn't have time or money. But if they come to those dispensaries near our village these women will be educated. (Glory)

Closely related to the limited access to treatment and pessaries was a lack of knowledge. Lack of knowledge about their condition, about the treatment options and also more practical aspects like where to go. A lack of knowledge through poor health education among Tanzanian women was one of the most frequent mentioned barriers for pessary use. Many of the study participants were well-informed but outlined lack of knowledge about pessaries as one of the biggest barriers for women to get treatment,

As for me I have accepted it, but other women need more information about this because most think this instrument [ed. pessary] is cancerous. [...] Due to fear, yes, they prefer using pieces of cloth than this [ed. pessary]. They need more education about this and as for me I didn't have a problem accepting it. (Mary)

A few of the women had tried seeking treatment before getting their pessary. Their experiences were quite similar with healthcare personnel who were not able to diagnose and treat their condition. Editha had this experience,

Yes, I already came to the hospital and explained how I felt. They examined me and told me that I have UTI [ed. urinary tract infection]. I was given medications, but the problem did not stop. I still felt pain in this area [ed. she pointed to her lower abdomen]. I once came to the hospital [...] [ed. I] was told nothing is wrong. (Editha).

Emotional

Together with 'lack of knowledge', shame was a returning theme when the women spoke of barriers for pessary use. Some could see a general tendency among women being ashamed of their condition while others had experienced the shame first-hand like Perucy,

Yes, I haven't gone anywhere, because in our African society, it's embarrassing when people start pointing fingers at you because of the problem you have. [...] I haven't gone there [ed. to traditional healers], I just stayed quiet. (Perucy)

Shame were also hindering the women in sharing their experience with other women,



First, I feel shy explaining to people that I have urine incontinence because everyone has a different view on why there's urine leaking, and everyone will perceive that differently. So, I decided that it will be my secret with the doctor. (Editha)

In general, the women shared their pessary experience with their husbands and most husbands approved of the pessaries as they could see an improvement in the women's condition. However, Monalisa shared some experiences described by other women,

I have heard others [ed. women] saying their husbands don't like it. It's okay if he doesn't like it but who is suffering? (Monalisa)

Although it did not stop them from using their pessaries, some women found that their husband or sexual partner questioned pessary use. Victoria described it like this,

I really don't know [ed. why he didn't like it]. It's just a feeling or someone's mind. I never understood why because I told him and showed it to him [ed. the pessary] and he wasn't happy, and I didn't want to make him sad or angry, so I used to remove it [ed. while having sexual intercourse]. (Victoria)

DISCUSSION

This study showed that long-term vaginal pessary use for SUI among Tanzanian women is challenging but also highly beneficial. The main motivating factors for seeking treatment were symptoms, social consequences and low quality of life. Once fitted with a pessary the women experienced a clear improvement in their condition including symptom relief, better quality of life and a richer social life. Even though these women were prepared to share their experiences in order for more women to benefit from the treatment there are some barriers that pessary users have to overcome. Shame, husband's disapproval and limited access as well as lack of knowledge are all factors that prevent the women of Tanzania from getting the treatment they need. Therefore, the findings of this study indicate that if pessary treatment is to be implemented in Tanzania, it needs to come with a basic health education for women and better access to treatment.

To our knowledge, this is the first study in an African country with a long-term follow-up of women who have received pessary treatment for SUI. The comparability of this study's results is therefore limited. However, two similar studies have been conducted in Canada and USA with Caucasian women using pessaries for UI and pelvic organ prolapse and Latina women using pessaries for pelvic organ prolapse, respectively. Since the treatment for stress urinary incontinence and pelvic organ prolapse are quite similar, we find that the results are comparable. In line with our study, both the Canadian and American study found that the pessaries relieved symptoms and

improved quality of life after the adaptation process.^{16 21} Along with a new American study, they also found the same importance of knowledgeable and helpful health-care personnel in order to get the women to accept and sustain treatment.^{16 21 22} The explanation to this could be the lack of knowledge about pessary treatment for pelvic floor disorders that we found in our study and that Maldonado *et al* and Brown *et al* found in their studies as well.^{22 23}

However, in contrast to this study, both the American and Canadian study described the difficult choice women had to make when deciding what treatment, they wanted. The pros, the cons and the possible implications on their lives were discussed with their physicians. In our study, the struggle was not on what treatment to choose but simply to have access to the treatment. The women in our study did not seem to see it as a choice. They were provided with an option for treatment they did not have in the first place, and they accepted the physician's recommendations gratefully and unquestionably.

Another contrasting finding is the adaptation process. The Canadian women and some Latina women had many difficulties in adapting to the pessary and some found it impossible to perform pessary self-care.^{16 21} The women in our study hardly saw pessary self-care as an issue.

The reasons for the partially different themes in the studies can possibly be found in different inclusion criteria and cultural differences. In our study, we included women that on average were younger and had longer experience with pessary use compared with the American and Canadian study.^{16 21} Hunskaar found that age is a variable that affects how women experiences their symptoms.⁶ Age might also affect the women's views on what challenges pessary use presents in different stages of life. In regard to the length of pessary experience the women might change focus from the initial concerns in the adaptation process to how they want to live their lives, free of symptoms. Lastly, the cultural differences between the Western countries and African countries are noticeable and could contribute to the differences found. However, further research is needed to confirm these hypotheses.

Limitations

This study illustrates life with a pessary as experienced by a selected group of Tanzanian women living in the Kilimanjaro Region. A limitation of this study is that we only included women with more than 18 months of pessary experience as we wanted to assess long-term pessary use, and therefore we excluded women who had stopped using their pessary. Women who discontinued to use their pessaries might have had different views on pessary use, and therefore this study only offers a small piece to the full picture of barriers for pessary use. However, it was without the scope of this study to include these women, and we recommend future studies to also include the perspectives of these women.

The PEDITA study, from which we recruited our participants, used the questionnaires Urogenital Distress

Inventory (UDI-6) and Urinary Incontinence Questionnaire (UIQ) to quantitatively assess the women's satisfaction with pessaries, and these findings have been published elsewhere.¹² We chose a qualitative approach for this study in order to nuance the women's experiences and get an in-depth perspective of the pros and cons of pessary use. Yet, this approach makes it harder to compare our findings to other studies and to use the data for patient counselling and decision-making. However, it does give us an understanding of the more complex and unquantifiable aspects of pessary use.

The interviews were conducted with a nurse translating from English to Kiswahili and back. The translation link can minimise the depth of the qualitative data. However, we believe this issue to be minor as the women were happy to share their experiences. The interviews, analysis and manuscript were all done by the same researcher and several measures were taken in order to avoid ineligibility. During the interview process an experienced Tanzanian nurse recruited women by phone and translated during the interviews. The audio files were transcribed and translated by two experienced Tanzanian medical students who validated the translation.

CONCLUSION

Life with a pessary is complex and has many facets. Tanzanian women are motivated for pessary use and have positive experiences with pessaries as a treatment that relieves their symptoms and improves their quality of life. However, the barriers are not to be ignored and access, health education, shame and husband approval are key elements in sustaining a successful course of treatment. Therefore, the results of this qualitative study suggest that pessary treatment can be implemented on a large scale in Tanzania if it comes with a basic health education for women and better access to treatment.

Author affiliations

¹Department of Clinical Research, University of Southern Denmark, Odense, Denmark

²Department of Obstetrics and Gynecology, Kilimanjaro Christian Medical Centre, Moshi, Kilimanjaro, Tanzania, United Republic of

³Kilimanjaro Christian Medical College, Moshi, Kilimanjaro, Tanzania, United Republic of

⁴Department of Obstetrics and Gynaecology, Odense Universitetshospital, Odense, Denmark

⁵OPEN, Odense Patient Data Explorative Network, Odense University Hospital, Odense, Region of Southern Denmark, Denmark

Twitter Benjamin C Shayo @drbenshayo and Ditte Søndergaard Linde @ditte_linde

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval Joint ethical clearance for the overall PEDITA study was obtained from the Kilimanjaro Christian Medical University College's Clinical Research Ethical Review Committee (certificate number 811).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Additional unpublished data concerning experiences with pessary use are available. This includes interview data with women suffering from pelvic organ prolapse and their perspective on pessary use. We aim to publish these findings in the future.

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ORCID iDs

Karina Holm Nissen <http://orcid.org/0000-0003-3102-987X>

Ditte Søndergaard Linde <http://orcid.org/0000-0002-0851-6760>

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