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Perceptions of pelvic floor dysfunction and rehabilitation care amongst women in southeast China after radical hysterectomy: a qualitative study

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Abstract

Objective: To investigate the perceptions of pelvic floor dysfunction (PFD) and rehabilitation care amongst women after radical hysterectomy and to explore ways to improve quality of care.

Methods: Thirty-six women who underwent radical hysterectomy at a hospital in southeast China were enrolled via purposive sampling. Semi-structured in-depth interviews were conducted. The texts were analysed via qualitative content analysis.

Results: Four themes were obtained: serious lack of knowledge, heavy psychological burden, different coping strategies and great eagerness to receive multiparty support on PFD rehabilitation care.

Conclusion: The society and professional staff should strengthen health education on PFD. Professionals should offer education before and after surgery and actively provide rehabilitation consultation to promote the availability of rehabilitation to support women with PFD rehabilitation care. In addition, family-centred care is an important way to support women to return to normal life, and women's need for family support should be more actively expressed. Moreover, knowledge of medical insurance should be popularised, especially in rural areas in China.

Keywords: Pelvic floor dysfunction, Radical hysterectomy, Perceptions, Rehabilitation care, Qualitative study

Introduction

Radical hysterectomy is one of the most recommended surgical procedures for gynaecological malignancies owing to its high treatment rate [1]. However, it substantially changes the overall structure of the pelvis, thereby unavoidably damaging pelvic floor tissues. The disruption of local nerve supplies and distortion of anatomical relationships in the pelvic floor after this operation may

lead to the development of diseases related to pelvic floor dysfunction (PFD) [2, 3].

PFD is defined as a broad set of pelvic floor conditions such as urinary incontinence, constipation, pelvic organ prolapse, sexual dysfunction and chronic pelvic pain syndrome [4]. These conditions impose heavy physical and mental burden to women and greatly influence their daily lives [5] and psychological health [6] by negatively impacting their self-care activity and family and work relationships. A study reported that the prevalence of PFD in low- and middle-income countries is 25% [7]. A recent meta-analysis of adult Chinese women noted that the prevalence of urinary incontinence is 31.1%, and it has remained at a high level since 2005 [8]. Pelvic organ

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prolapse also affects 9.67% of urban Chinese women [9]. A study in the USA showed that 66.8% of participants are not aware of pelvic floor rehabilitation to address PFD [5]. For women who develop PFD after undergoing radical hysterectomy, rehabilitation therapy and care are often the primary choice in postoperative rehabilitation; this treatment modality can remarkably improve PFD and prevent its development [10]. Ideally, rehabilitation care for women with this condition should be implemented in the early postoperative period to ensure recovery from this condition, which can effectively restore pelvic floor function and reduce the incidence of PFD [11].

However, women's perceptions of PFD considerably influence their choice and adherence to treatment and care [12]. Perception is to use self-cognition to explain sensory signals across multiple spatial and temporal scales, thereby leading to action [13]. Therefore, the perceptions of PFD and rehabilitation care are the key to the recovery of pelvic floor functions of women after radical hysterectomy. To the best of our knowledge, the perceptions of PFD and rehabilitation care amongst Chinese women after radical hysterectomy have not yet been explored. Therefore, this study aimed to investigate the perceptions of PFD and rehabilitation care amongst women who underwent radical hysterectomy to explore ways to improve quality of care.

Materials and methods

This study was conducted at a provincial hospital in southeastern China from March 2019 to July 2019. Women who underwent radical hysterectomy were recruited via purposive sampling according to their education levels, i.e., junior secondary education (9 years), senior secondary education (12–13 years) and higher education (15–19 years) [14]. Eligible women were approached and invited to participate in the study by a senior nurse working in the gynaecological oncology department of the provincial hospital. The inclusion criteria were as follows: women who underwent radical hysterectomy, including open radical

hysterectomy and laparoscopic radical hysterectomy; those who had no serious complications; those without psychological and mental illness; those who were fluent in Mandarin; and those who signed informed consent. Participants were excluded if they were unable to complete the interview because of insufficient interview time or were emotionally unstable during the interview. Enrolments of participants were determined by the principle of data saturation. This study was approved by the Ethics Committee of the First Affiliated Hospital of Fujian Medical University (FAHFMU [2018] No. 073).

Data were collected via semistructured individual interviews. A self-development interview guide consisting of nine questions about the perceptions of PFD and rehabilitation care was used for data collection (Table 1). Following the interview guide, a researcher (Y. L.) interviewed each participant face-to-face for 30–45 min in a separate and quiet room at the hospital. The interviewer noted the nonverbal behaviour of the participants. The entire interview was recorded using a digital audio recorder. Then, the researcher (Y. L.) transcribed the participants' responses verbatim into Chinese text within 24 h after each interview. The texts were translated into English by Y. L. (a master student of nursing with bilingual skills) and L. G. (a Ph.D. in nursing from Sweden with rich experience in qualitative research).

Data were analysed using the qualitative content analysis described by Graneheim and Lundman [15]. The analysis included manifest and latent content analysis as follows: (1) the text was read several times to obtain a whole sense of the participants' perception of PFD; (2) the text content was divided into meaning units according to the meaning of expression; (3) the meaning units were compressed and extracted into codes; (4) differences and similarities between codes were compared, and then the sorted codes with commonality were grouped into categories, i.e., manifest content analysis; and (5) the research team fully considered the social and cultural contexts of the interview content, discussed the formed

Table 1 Interview guide: questions about the perceptions of PFD and rehabilitation care amongst women after radical hysterectomy

What do you know about female pelvic floor function?
If a woman has PFD (such as urinary incontinence), what do you think is the cause?
How does radical hysterectomy affect you?
What is your biggest concern after radical hysterectomy?
How do you think radical hysterectomy will affect pelvic floor function?
What will you do to treat PFD?
What do you think about the rehabilitation care of pelvic floor function?
How do you think rehabilitation care of pelvic floor function will affect you?
What are the factors that affect your rehabilitation care of pelvic floor function?

codes and categories and linked the underlying meanings to form themes, i.e., latent content analysis.

Results

Thirty-six women who met the inclusion criteria participated in this study. The mean age of participants was 49 years (range 42 to 58 years). Amongst the participants, 12 had a low educational level, 12 had a middle educational level, and 12 had a high educational level. The place of residence included rural area (n = 20) and urban area (n = 16). Seven participants had PFD symptoms before surgery. Half of the participants developed PFD symptoms after surgery. Twenty-eight participants were in the acute postoperative period within 3 months of surgery, whilst eight were in the postoperative follow-up period for over 3 months after surgery (Table 2). Four themes were formed from the interview texts: (1) serious lack of knowledge, (2) heavy psychological burden, (3) different coping strategies and (4) great eagerness to obtain multi-party support on PFD rehabilitation care (Table 3).

Serious lack of knowledge

The first theme consisted of two categories: 'limited knowledge of PFD' and 'limited knowledge of pelvic floor rehabilitation care'.

Limited knowledge of PFD

Limited knowledge of PFD was reflected amongst most participants, regardless of whether she was in the acute or follow-up postoperative period. Most participants said that they were unaware of PFD: *'I don't know what this pelvic floor disorder means, I don't understand' (P14, postoperative period within 3 months, lived with PFD before and after surgery)*. However, after learning the symptoms of PFD, some of the participants suggested that their advanced age and childbirth might have caused the disease: *'The symptoms were normal. You know...so big surgery... It (nocturia) is not a disease. It needs to be slowly recovered. Do not need to see doctor for it' (P22, postoperative period over 3 months, lived with PFD after surgery)*. However, they were unsure if PFD was related to their radical hysterectomy: *'I think a good doctor and very accurate surgery will not cause problems in patient's pelvic floor function at all. I don't know whether previous surgery will cause this problem to women. I have never seen it before' (P6, postoperative period within 3 months, lived without PFD after surgery)*.

Limited knowledge of pelvic floor rehabilitation care

With regard to dealing with PFD, the participants did not know how to perform rehabilitation care, although some women recognised the efficacy of this treatment: *'When I stand up, I feel that something in my abdomen*

Table 2 Participant characteristics (n = 36)^a

Variable	Value
Age, years	49 (42–58)
Educational level ^b	
Junior secondary education (9 years)	12 (33.3)
Senior secondary education (12–13 years)	12 (33.3)
Higher education (15–19 years)	12 (33.3)
Place of residence	
Rural area	20 (55.6)
Urban area	16 (44.4)
Occupation	
Farmer	9 (25.0)
Chef	1 (2.8)
Staff	4 (11.1)
Teacher	5 (13.9)
Trader	8 (22.2)
Lawyer	2 (5.6)
Freelance	4 (11.1)
Retirement	3 (8.3)
Household income, yuan/month	
< 2,000	2 (5.6)
2,000–5,000	16 (44.4)
5,000–10,000	10 (27.8)
> 10,000	8 (22.2)
Did PFD occur before surgery?	
Yes	7 (19.4)
No	29 (80.6)
Did PFD occur after surgery?	
Yes	18 (50.0)
No	18 (50.0)
Disease type	
Uterine sarcoma	2 (5.6)
Ovarian cancer	11 (30.5)
Endometrial cancer	11 (30.5)
Cervical cancer	12 (33.4)
Surgical approach	
ORH	5 (13.9)
LRH	31 (86.1)
Postoperative time, month	
≤ 3 (acute postoperative period)	28 (77.8)
> 3 (postoperative follow-up period)	8 (22.2)

PFD pelvic floor dysfunction; ORH open radical hysterectomy; LRH laparoscopic radical hysterectomy

^a Values are given as mean (range) or number (percentage)

^b Classified according to the education statistic data in 2018[14]

will fall out, which should be related to the operation. I think the pelvic floor rehabilitation care may improve the situation, but I have no idea what I can do for it' (P23, postoperative period within 3 months, lived with PFD after surgery). Some of them even questioned its efficacy:

Table 3 Perceptions of PFD and rehabilitation care amongst women after radical hysterectomy**Serious lack of knowledge**

Limited knowledge of PFD

Limited knowledge of pelvic floor rehabilitation care

Heavy psychological burden

Fear and worry

Shame and self-contempt

Guilt and self-blame

Different coping strategies

Positive coping strategies

Passive coping strategies

Great eagerness to receive multiparty support on PFD rehabilitation care

Hope for receiving support from family members

Hope for receiving support from professionals

Hope for receiving support from society

'After this operation, my pelvic floor function was affected. The most obvious symptom is constipation. ...I think pelvic floor function rehabilitation seems to be a psychological comfort. No actual effect. This organ has already been cut off, so physiological change cannot be changed' (P15, postoperative period over 3 months, lived with PFD after surgery). Several women said that they would not seek pelvic floor function rehabilitation care if they did not have symptoms of PFD: *'Vaginal delivery may cause the symptoms of PFD, like sexual dysfunction and urinary incontinence. However, if I do not have symptoms of PFD, I will not consider pelvic floor rehabilitation care unless I have such symptoms'* (P9, postoperative period within 3 months, lived without PFD after surgery). Therefore, the participants were unaware of the importance of early rehabilitation care after surgery.

Heavy psychological burden

The second theme was further categorised into 'fear and worry', 'shame and self-contempt' and 'guilt and self-blame'.

Fear and worry

For the participants in the acute postoperative period, they felt more fear and were afraid. Some of them felt fear after experiencing PFD symptoms and were worried that they will no longer have a normal life: *'I fear, I fear that the urine cannot be closed...After I walk a little bit, urine can go itself. The smell...is bad (silence). My life is broken'* (P21, postoperative period within 3 months, lived with PFD after surgery). Under the threat of malignant tumours, some women were afraid to obtain unfavourable information regarding their disease: *'I do not*

want to ask anything (doctors)...Knowing too much will hurt me even more' (P10, postoperative period within 3 months, lived without PFD after surgery). Moreover, they were worried about their PFD symptoms worsening: *'Of course, I am anxious. I am worried day and night that something will fall out of my body. And I always feel empty in my lower abdominal. This feeling kept me cannot fall sleep all night.'* (P7, postoperative period within 3 months, lived with PFD after surgery).

Shame and self-contempt

As the postoperative time increased, the participants gradually paid attention to the distress caused by PFD. Stigma surrounding the problem of PFD contributed to participants feeling shame: *'It (PFD) is a terrible thing. I will feel ashamed if I say it (silence). People will say something bad if they know it...'* (P31, postoperative period over 3 months, lived with PFD after surgery). Moreover, they felt self-contempt because they lost their uterus, which meant that they lost their femininity, and they considered that they were no longer a full female: *'The psychological burden is very heavy, and I am self-contemptuous that I do not be like a whole woman after the operation (silent), just like what they say'* (P2, postoperative period over 3 months, lived without PFD after surgery).

Guilt and self-blame

Furthermore, a few participants narrated that their family had spent a lot of money for their treatment. Despite the intervention, they did not fully recover and remained sick because PFD appeared after the operation. Hence, they felt guilty and blamed themselves: *'After cost so much money on the disease, I would feel guilty if I am always a sick person after I go back home (silent). ... I don't want my family to be worried about me too much'* (P13, postoperative period within 3 months, lived without PFD after surgery). Several women apologised to their husbands for the shattered sex life, which limited their ability to fulfil marital roles: *'Tell you the truth... I did the operation and now I have the disease (PFD) again...At this point, I'm sorry for him (husband), I can only let him do whatever he wants'* (P4, postoperative period over 3 months, lived with PFD after surgery).

Different coping strategies

The third theme presented two completely different coping strategies from participants to deal with PFD: one was 'positive coping strategy'; the other was 'passive coping strategy'.

Positive coping strategy

Most women with PFD were being positive. They described that they adjusted their mentality: *'At the same*

time of treatment, I also adjust my mentality, should not be pessimistic. Even when facing a very serious matter, we must be optimistic and accept it' (P12, postoperative period within 3 months, lived with PFD after surgery). Moreover, they actively sought information regarding this condition, actively treated the disease and focused on their recovery. As one woman said, 'First found it out from internet how to deal with it. Then, I went to the hospital for help...' (P11, postoperative period within 3 months, lived with PFD after surgery). Another woman pointed out, 'I am doing whatever the doctor says. I rest more, exercise properly, and eat more for nutrition' (P23, postoperative period within 3 months, lived with PFD after surgery).

Passive coping strategy

However, one woman did not seek treatment and merely accepted her situation as 'destiny': 'I think... Everyone has everyone's fate. It is destined, can't be changed... Look at me, my pelvis always feels a little pain and constipation occurs frequently, but I think it's nothing...It is better to let nature take its course instead of fighting against the fate... Accept the arrangements of fate' (P25, postoperative period over 3 months, lived with PFD after surgery). Some women only went to see a doctor when their symptoms started to affect their lives: 'Well, if it doesn't affect my normal life and work, I usually don't go to the hospital, unless the symptoms of PFD are very serious' (P29, postoperative period within 3 months, lived with PFD before surgery). One woman completely stopped seeking help because of her advanced age: 'My life is definitely getting worse because of the symptom (frequent urination) ...I didn't see doctor. Life is getting worse day by day if you are old. It doesn't matter' (P1, postoperative period over 3 months, lived with PFD after surgery).

Great eagerness to receive multiparty support on PFD rehabilitation care

The fourth theme was great eagerness to obtain multiparty support for PFD rehabilitation care, which included 'family support', 'professional support' and 'social support'.

Hope for receiving support from family members

All women hoped for understanding from their family members: 'My family refused to pay the cost (silence)... They do not understand my suffering...' (P18, postoperative period within 3 months, lived with PFD after surgery). Although the participants gradually recovered with time, their energy was inevitably affected, and they hoped that family members could take some of their workload: 'I have a shop...I still don't have energy now... I have to work in my shop as soon as I am discharged from hospital.

I need my family help me...' (P13, postoperative period within 3 months, lived without PFD after surgery). They also hoped to obtain decision support from their husbands in seeking rehabilitation and treatment: 'I do not know whether my husband permit me see doctor or not. I will come if my husband let me come' (P30, postoperative period within 3 months, lived without PFD after surgery).

Hope for receiving support from professionals

Most of the participants indicated that professional support was necessary. They hoped that health-care staff could provide professional knowledge, skill support and care for them: 'My friends and I never heard about it (PFD)... Doctor and nurse teach me how to exercise. I want to know more from them. I do want that they can teach me more and guide me more' (P6, postoperative period within 3 months, lived without PFD after surgery). Moreover, they stated that they would adhere to the health-care staff's suggestions: 'Leaking urine makes me feel embarrassed. I don't dare to talk about it to others... Doctors and nurses are professionals. I especially hope that they can understand me and care me. I will at least relieve some of my anxiety' (P16, postoperative period within 3 months, lived with PFD after surgery).

Hope for receiving support from society

The participants also hoped to receive social support. One woman said that lack of money was a reason for her delay in seeking treatment, so she wanted to receive financial support from the government: 'The cost of rehabilitation is too much for me... How can I still have money to go to the hospital for it, unless government gives me financial support' (P4, postoperative period over 3 months, lived with PFD after surgery). They believed that poor awareness of PFD in society played an important role when they sought support from society and even from family members: 'Although I often read popular medical magazines, I was blank in this field before the doctor told me about the knowledge of pelvic floor dysfunction. I do think it is not known well by people in society. How can we get understanding and support from people around and society?' (P26, postoperative period within 3 months, lived without PFD after surgery).

Discussion

This study presented that serious lack of knowledge played a major role that hindered early postoperative PFD rehabilitation care. Most participants stated inadequate knowledge about the meaning, cause of symptoms, effects and treatment of PFD, regardless of the postoperative period or whether or not they lived with PFD before and after the operation. On the one hand, it was may be because that all participants suffered from

malignant tumour. They focused on treatment and surgical removal of the tumour whilst ignoring the impact of surgery on pelvic floor function. This observation was consistent with the rule of perception, i.e., humans focus on more important tasks in a complex environment [16]. In some participants' view, malignant tumours also increased their fear of disclosing their condition and affected their initiative to obtain relevant knowledge about PFD and rehabilitation care. On the other hand, there is a huge knowledge gap of PFD amongst the public [17], which seriously influences the attitudes and behaviours of women and other people in their social circle toward rehabilitation care of PFD [18]. Most participants did not know that radical hysterectomy would result in PFD and described PFD as a 'terminal illness'. The positive perceptions about pelvic floor rehabilitation could be not supported by a low level of public awareness about PFD prevalence and treatability. Therefore, health education about PFD and rehabilitation care is urgently needed. Participants pointed out that they hope to obtain relevant health information and rehabilitation guidance through professional channels. Therefore, knowledge of PFD and rehabilitation care should be popularised and strengthened in hospitals and society via multiple channels, such as brochures, posters, Internet, television and radio. Meanwhile, early postoperative rehabilitation can effectively restore pelvic floor functions and reduce the incidence of PFD [19]. Professional staff should grasp the opportunity of health education on PFD rehabilitation care in the hospital.

The present study indicated that amongst participants, losing their uterus meant losing their femininity, which made them reassess their female value and shame on the loss. They had to perceive themselves as a different person but not a normal woman [20]. The participants also feared the progression of their diseases and postoperative changes in their body. Postoperative PFD-related symptoms made them deny themselves and develop negative emotions, such as guilt and low self-esteem, which seriously affected their quality of life. This is similar to women who experienced pelvic floor trauma after vaginal birth [21]. A study showed that feelings of shame about the disease is the main factor why women do not see a doctor [22]. However, the women in the present study affirmed that they were eager to receive professional help. Therefore, health-care professionals should focus on the psychological and mental health of affected women, strengthen their confidence that they would recover and enhance their sense of self-worth whilst conducting health education/pelvic floor function rehabilitation care. In addition, an excellent intervention might be to organise a group of women who suffer from PFD with the assistance of health-care professionals. Doing so might

alleviate their suffering and allow them to receive understanding and support from each other.

The interviews revealed that most of the participants adopted positive coping strategies in the face of PFD after radical hysterectomy. However, some of them adopted negative coping strategies, such as seeing a doctor only when the symptoms had affected their lives; gave up seeking help; and accepted their condition as their fate. Several reasons may explain these appearances. Firstly, some of them believed that PFD is an inevitable suffering brought by aging, and disease management is unnecessary in their old age. This belief was similar to that described by Vethanayagam et al. [23]. Secondly, the public's misconceptions about PFD stigmatised women with this disease because of poor social awareness. The stigma reduces the possibility of women disclosing their illness and seeking help [24]. Thirdly, owing to the overarching influence of traditional Chinese concepts, some women in rural areas have a low degree of self-identity and largely rely on their husbands when it comes to making decisions about major family affairs [25]. As wives and mothers, women in traditional Chinese culture assume the responsibility as caregivers in the family, prioritising family obligations over their own health and hiding their own needs to decrease the burden on the family [26]. These reasons not only highlighted the importance of popularising PFD knowledge in society but also emphasised the importance of improving women's self-identity.

An effective support system for individuals can reduce psychological burden, improve the level of disease response and ultimately promote disease recovery [27]. Family members usually promote disease recovery with economic, physiological, psychosocial and decision support. The participants hope that their families can share some tasks such as housework so that they can focus on PFD rehabilitation. All of them hoped to receive understanding and support from their families, especially from their husbands. Given that PFD is related to privacy and sex, understanding and support from husbands are especially important. The closer the family relationship is, the stronger the couple's coping ability will be and the better they can deal with the problems caused by the disease [28]. Therefore, family-centred care is an important way to support women with PFD. Health-care professionals should focus on husbands, help women receive understanding and support from family members and encourage family members to actively participate in women's rehabilitation care.

Moreover, the participants hoped to receive social support. Social support can not only promote patients' healthy behaviours but also promote their compliance with medical regimens [29, 30]. This study shows that lack of treatment costs can delay participants in seeking

treatment for PFD. Thus, they hope that the government can provide financial support for PFD rehabilitation care, such as including PFD rehabilitation in the basic medical insurance reimbursement to reduce the financial burden on women and increase their willingness to seek medical help. In addition, the medical insurance system in China covers all Chinese citizens living in the country. Thus, people can obtain preferential medical treatment at a relatively low price [31]. However, some women from rural areas said that they did not have medical insurance, suggesting that the public, especially in rural areas, lacks knowledge not only of PFD but also of medical insurance.

This study has several limitations. Firstly, the data may not be sufficient. The results might have been affected by some nuances in the translation of the texts from Chinese to English. Nevertheless, a qualitative study through detailed interviews and observations can provide insights into individuals' thoughts, behaviour and understanding in life [32]. This study offered evidence on the low perception of PFD and rehabilitation care after radical hysterectomy amongst women and society. This study explored the underlying reasons and provided specific ways to improve the quality of care for women with PFD.

In conclusion, this study found that women who underwent radical hysterectomy in southeast China seriously lacked knowledge about PFD and rehabilitation care. Our data showed that women after radical hysterectomy bore a burden of physical discomfort and stigma because of inadequate information on PFD and rehabilitation care. The low awareness of PFD in society was also an important reason that women did not obtain more support from society and family members. Therefore, it is necessary to popularize PFD health knowledge in order to raise public awareness of PFD. Moreover, knowledge about pelvic floor rehabilitation should be imparted to women before radical hysterectomy. Professional staff should more actively inform patients about the symptoms of pelvic floor function damage that may be caused by radical hysterectomy, and actively provide patients with rehabilitation counselling before and after surgery. Professional staff should provide encouragement to patients to make them understand that they are there to provide help when symptoms of PFD worsen or persist. The knowledge of medical insurance should also be promoted in rural areas of southeast China. Family-centred care could be an important approach in the recovery of women with PFD. Women should be encouraged to express their needs for family support about postoperative recovery more broadly.

Acknowledgements

We are grateful to everyone in the First Affiliated Hospital of Fujian Medical University who helped with recruitment and all participants who shared their valuable experiences in this study.

Author contributions

Y. L. participated in the design of the study, data collection, data analysis and writing of the main manuscript text. A. L. participated in the design of the study, data collection, data analysis and preparation of the manuscript. Z. Z. participated in data analysis, interpretation and critical revision of the manuscript for important intellectual content. Y. W. participated in data analysis, interpretation and critical revision of the manuscript for important intellectual content. H. Y. participated in data analysis and preparation of the manuscript. X. J. participated in data analysis and preparation of the manuscript. L. G. participated in the design of the study, data analysis, preparation of the manuscript, interpretation and critical revision of the manuscript for important intellectual content. All authors read and approved the final version of the manuscript.

Funding

No funding received.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Ethics Committee of the First Affiliated Hospital of Fujian Medical University (Ethics Approval Number: FAHFMU [2018] No. 073). All participants signed informed consent. We also confirm that all methods were carried out in accordance with the regulations of the Declaration of Helsinki.

Consent for publication

Not applicable.

Competing interests

All authors declare that they have no competing interests.

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Received: 28 May 2021 Accepted: 24 March 2022

Published online: 09 April 2022

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