

Women's strategies for coping with urinary incontinence*

ESTRATÉGIAS DE ENFRENTAMENTO DA INCONTINÊNCIA URINÁRIA POR MULHERES

ESTRATEGIAS DE ENFRENTAMIENTO FEMENINO DE LA INCONTINENCIA URINARIA

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ABSTRACT

This article is part of a more comprehensive qualitative study which used grounded theory and symbolic interactionism as theoretical and methodological frameworks, resulting in the theoretical model entitled, *Between suffering and hope: rehabilitation of urinary incontinence as an intervenient component*. In order to communicate all the knowledge produced, part of this model is presented, and it refers to the process of coping with urinary incontinence by women without perspectives of access to surgical treatment after failure of conservative procedures. When interrelating the components (categories and subcategories) of these women's experience in order to compare and analyze them to understand their interaction, moral and psychosocial vulnerability were noticed within the experience of the group, which makes them susceptible to health risks and to compromise of their quality of life, observed in the movement of the group's experience. Research is needed to further understand experiences in which there are barriers to surgical treatment due to physicians' disbelief in its effectiveness.

DESCRIPTORS

Urinary incontinence
Women
Rehabilitation
Surgery
Life change events

RESUMO

Este artigo é parte de uma pesquisa qualitativa mais abrangente que utilizou como referencial teórico-metodológico a Grounded Theory e o Interacionismo Simbólico, resultando no modelo teórico denominado "Entre o sofrimento e a esperança: a reabilitação da incontinência urinária como componente interveniente". Com a intenção de comunicar todo o conhecimento produzido, apresenta-se parte desse modelo, referente ao processo de enfrentamento da incontinência urinária por mulheres sem perspectivas de acesso ao tratamento cirúrgico, após falha dos procedimentos conservadores. Ao inter-relacionar os componentes (categorias e subcategorias) relativos à experiência dessas mulheres, buscando compará-los e analisá-los para compreender a interação entre eles, notou-se vulnerabilidade moral e psicossocial no movimento da experiência do grupo, suscetibilizando-o a riscos à saúde e ao comprometimento da qualidade de vida. Pesquisas são necessárias para aprofundar a compreensão de experiências em que haja barreira ao tratamento cirúrgico por descrédito do profissional médico sobre sua efetividade.

DESCRITORES

Incontinência urinária
Mulheres
Reabilitação
Cirurgia
Acontecimentos que mudam a vida

RESUMEN

El artículo forma parte de una investigación cualitativa más abarcadora que utilizó como referencial teórico-metodológico la Grounded Theory y el Interaccionismo Simbólico, resultando en el modelo teórico denominado "Entre el sufrimiento y la esperanza: la rehabilitación de la incontinencia urinaria como componente interveniente". Con intención de comunicar el conocimiento producido, se presenta parte de dicho modelo, referido al proceso de enfrentamiento de la incontinencia urinaria en mujeres sin perspectivas de acceso a tratamiento quirúrgico, habiendo fallado los procedimientos conservadores. Al interrelacionarse los componentes (categorías y subcategorías) relativos a la experiencia de dichas mujeres, buscando compararlas y analizarlas para entender su interacción, se notó vulnerabilidad moral y psicossocial en el tránsito de experiencia grupal, susceptibilizándolo a riesgos de salud y al compromiso de calidad de vida. Serán necesarias investigaciones que profundicen la comprensión de experiencias en las que existan obstáculos al tratamiento quirúrgico por descreer el profesional médico sobre su efectividad.

DESCRIPTORES

Incontinencia urinaria
Mujeres
Rehabilitación
Cirugía
Acontecimientos que cambian la vida

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INTRODUCTION

Urinary incontinence (UI) is considered a public health issue worldwide and is epidemiologically relevant, although still invisible within public policies, to professional educational organizations and, consequently, to clinical assessment and interventions. This context has been imposing an experience of difficulty in coping for millions of people around the world, especially women, because they do not benefit from technical and scientific knowledge focused on prevention and rehabilitation of UI.

Urinary incontinence and lower urinary tract dysfunctions (LUTD) are recognized as a silent epidemic worldwide⁽¹⁾. Only in 2005, during the Third International Conference on Incontinence, held in Paris, was it considered the third largest health issue after heart diseases and cancer, primarily affecting women at different ages, regardless of economic class and cultural pattern⁽²⁾.

Although the World Health Organization (WHO) started considering UI a disease in 1988, rather than a condition, by taking into account its debilitating effects related to health and well being, it was not included in the International Classification of Functioning, Disability and Health (ICIDH-2) until 2001, when it was included in the International Classification of Diseases (ICD-10)⁽²⁾.

This fact, in the following year, led the International Continence Society (ICS) to consider UI as a complaint of any involuntary leakage of urine described by specification of the relevant factors, such as: type, frequency, severity, precipitating factors of social impact, effects on hygiene and quality of life, measures to contain the leakage, and whether the individual, caregiver or partner seeks or wishes to seek health professional help for this issue. In that same report, ICS started classifying UI into six types: effort UI (EUI), urge UI (UUI), mixed UI (MUI), nocturnal enuresis, continuous urinary incontinence (CUI) and situational incontinence⁽³⁾.

Urinary incontinence affects approximately 25 million American adults, whereas EUI affects 50% of women, especially younger women, with symptoms worsening as age advances⁽¹⁾.

In the UK, about 30% of individuals aged 40 years or more experience some form of LUTD and the prevalence of UI with episodes of involuntary urine leakage occurring several times a month was estimated at 14%. These results are similar to those of a European study⁽¹⁾. In Korea, UI in women aged 30 to 39 years old was 36%, followed by 53% at ages 40-49, 45% at 50-59 years old, and 63% in individuals over 60 years old⁽⁴⁾; whereas in Sweden, UI was reported by 39% of the elderly⁽⁵⁾.

In Brazil, the national prevalence of UI is still unknown, because research conducted so far has focused on cities in São Paulo state. One study conducted in the capital, evidenced 20% of elderly patients with UI, out of which 16% were 60 to 74 years old and 33 were 75 years or older. In women, this prevalence was 26%, much higher than in men, 11%⁽⁶⁾. In another study conducted within São Paulo state, the prevalence of UI in women was 30%⁽⁷⁾.

The higher prevalence of UI in women at any age is justified by many causes, mainly pregnancy, delivery and hormonal changes in menopause. Other risk factors include obesity, gynecological surgeries, constipation, chronic diseases, heredity, use of certain drugs, caffeine intake, smoking and physical exercise, as well as several pathophysiological and situational processes⁽²⁾.

Given the relevance of the issue, the work of the authors of this study who care for women with UI, as well as the lack of epidemiological and qualitative studies exploring the experience of Brazilian women with the disease, a question arose: what is the lived experience of these women?

To address this concern, extensive research was performed aiming to understand the experience of women with UI and to develop a theoretical model which represents it, precisely at this stage when the country faces an aging population, in order to improve the understanding of the subject, since studies using the chosen theoretical and methodological framework were not found.

This study is part of that research and it aims to present the strategies for coping with UI used by women without any perspective of rehabilitation through surgical procedures, even after failure of conservative procedures.

Urinary incontinence (UI) is considered a public health issue worldwide and is epidemiologically relevant, although still invisible within public policies, to professional educational organizations and, consequently, to clinical assessment and interventions.

METHOD

This was a qualitative study which began after approval by the Research Ethics Committee (OF 048/06) and obtaining of informed consent for participation of adult and elderly women with the medical diagnosis of UI registered in a physical therapy clinic linked to the Unified Health System (SUS) at Universidade do Sagrado Coração, in Bauru, São Paulo, Brazil.

Data collection was performed by one of the researchers from 2007 to 2009, using the technique of non-directive interview, using the guiding question: How has your experience been with your UI?

The interviews were audio recorded and conducted in a place chosen by the women, ensuring privacy and anonymity of the information. In the end, the interviews were

transcribed and subjected to manual analysis, conducted by the researchers, according to the four steps proposed by the methodological framework of grounded theory: micro-analysis, open coding, axial coding, and selective coding⁽⁸⁾.

Respecting the steps proposed by the provided reference, theoretical saturation was obtained from the analysis of the 18th interview with women affected by UI, aged 41 to 81 years old, all with confirmed medical diagnosis, although seven had discontinued the treatment, seven were under conservative treatment and four were post-conservative treatment.

The choice of the age group above 40 years was intentional, as well as the pursuit of women attended in a physical therapy clinic. In the first case, because the scientific literature shows increased incidence of UI with advancing age⁽¹⁾ and in the second case, in order to explore the experiences of women attended by SUS who had access to physical therapy treatment.

The theoretical model emerged from the analysis process - Between suffering and hope: rehabilitation of UI as an intervening component⁽²⁾ - was submitted to validation, with the data being able to explain the experiences.

This article will present part of this model, referring to categories and subcategories that emerged during the data analysis on the experience of women with UI, called *Drawing on palliative strategies when possibilities for improvement are not seen*.

Thereby, the experience of women are discussed who, after failing conservative therapy, considered themselves without the possibility of access to surgical treatment. The reasons were related to lack of clinical condition (two women) and to medical professional discrediting the effectiveness of surgical treatment (eight women). This experience was analyzed in light of the theoretical framework of symbolic interactionism⁽⁹⁾ and according to the production of knowledge about the research subject.

RESULTS

Results portrayed the experience of that group of women taken from the feeling of sadness at seeing themselves dependent on palliative strategies for IU, through the frustrations with conservative treatment and having no hope of rehabilitation by means of surgical treatment, due to lack of a clinical condition for such or for the effectiveness of this treatment being discredited by the medical professional. This subprocess of the theoretical model emerged gathering the chaining of the five categories presented, subsequently, by the letters A, B, C, D and E.

Category A. Not obtaining improvement with conservative treatments

It was the understanding of these women that their efforts to adhere to conservative treatments, either physical

therapy or drugs, had failed, i.e. that stage of the rehabilitation process has not been enough to eliminate the UI.

(...) I did not get better either with physical therapy or with the drugs (...). Besides, the fact that the physical therapist inserted and removed a kind of vibrator in my vagina hurt me and caused a lot of pain (...) (Woman 4).

Category B. Experiencing UI again after periods of continence

This meant experiencing urine leakage again after reaching a period of continence through conservative treatments, sometimes abandoned by the women.

(...) My incontinence returned, a little milder than before, but it returned with coughing and sneezing and because I stopped doing physical therapy (...) (Woman 16).

Category C. Physician discouraging surgical treatment

This was the discouraging posture adopted by physicians about referring women for surgical treatment who did not recover from UI through conservative treatments, regardless of the presence of clinical conditions for such.

(...) I'm discouraged. I've tried everything to solve my UI and now the doctor told me that, talking to some of his colleagues, they have also realized that surgery to lift the bladder has not solved the problem (...) (Woman 2).

(...) The doctor does not want to operate on me, because besides being incontinent, I'm also diabetic and hypertensive. He told me that because of diabetes I'd better hang on without surgery, but that has caused much trouble in my life (...) (Woman 18).

Category D. Losing hope of eliminating the problem

This meant the loss of any expectation of seeing oneself rehabilitated from a problem that undermined one morally, physically, psychologically and socially.

(...) So, that is my life: either I go to the doctor and he operates on me or I have to resign, and be like this until I die. Then I die and will not urinate anymore (Woman 2).

Category E. Adopting palliative strategies to avoid being wet

This meant the use of a set of attitudinal (bodily, mental and social) or material resources, aiming to temporarily reduce the vulnerability of seeing oneself or being seen as incontinent; however, for that group of women who lost hope of eliminating UI, there was a great chance of a permanent situation of dependency on such resources. This category assembles nine subcategories presented subsequently.

Quitting social, leisure and spiritual activities for a long time

This is one of the strategies used by incontinent women which moves them for a long time into seclusion from

social activities done prior to UI and who now, because of the fear of being in a state of urinary urgency and the danger of finding themselves incontinent in public, stop doing activities that gave them pleasure.

(...) I was blocked from what I did before, such as walks, trips, receptions that extended too much, masses and church festivities (...) (Woman 1).

(...) I do not attend social events anymore. Sometimes I have the opportunity to have a snack with a friend. I go, but I know I'm at the house of a very acquainted person and where can I use the bathroom (...). Thus I am less afraid of looking bad when I'm with people I know than in places where I might draw attention to it, with strangers (...) (Woman 3).

Attending places with toilets available

This signifies one of the strategies used by women with UI which consisted of attending only places with toilets available to the public, and even then, being careful to be aware of their location, because their experiences have shown that people are not always sympathetic to offer a bathroom in time of emergency, whether residential or commercial, especially if not a customer.

(...) The other day, I ran to a bank and to a store because where I was I was not allowed to use the bathroom, for not being a customer. As I ran to find a bathroom, urine was leaking (...) (Woman 18).

Using urine collectors

This strategy involves the use of noninvasive urine collectors, so-called *little pieces of cloth* or even towels, tampons or adult diapers. There are reports on the use of basins near the bed, especially at night, to prevent loss of urine along the house while the woman with UI tries to get to the bathroom. The collector is chosen according to the volume of urine leakage and the dependence of women on the availability of toilets. Additional devices are usually taken in personal purses to meet the needs of change; thereby the dependence of women on these devices is evaluated as unpleasant.

(...) During the day, I put on a little piece of cloth (...) A nurse told me to use cloth instead of tampons, because it heats up more. I have two types, the smaller one I use during the day and the bigger one I use at night. I have done this for two years (...) (Woman 14).

Stopping antihypertensive when leaving home

This was a strategy used by women under drug treatment for arterial hypertension, who, in order to reduce urine volume, extended the schedule or stopped taking anti-hypertensive drugs, especially diuretics.

(...) Today I took four pills for hypertension, but did not take the diuretic because I have to leave (...) (Woman 3).

Reducing fluid intake

This was a strategy used by women with UI in order to decrease the urinary volume by reducing the water intake.

(...) A little extra water I take makes me feel like going to the bathroom (...). So I'd better not take it (...) (Woman 7).

Taking sedatives in order to sleep

This signifies the use of drugs that induce sleep due to the concern that nocturnal enuresis is a trigger of insomnia in women with UI.

(...) I have lost confidence in my ability to hold urine. This has hindered my sleep; so, if I want to sleep, I have to take sleeping pills (Woman 2).

Being careful with the choice of clothes and frequency of exchanges

This is one of the strategies used by women with UI to disguise from the public possible leaks of urine on clothing, such as being careful to choose dark clothes, not using skirts or dresses, as well as having an outfit that can cover up the signs of wetness. Moreover, having clothes with them is always one more possibility of providing an exchange, especially for those women who decline to use collectors.

Once I was working and started to sneeze and urinated in all of my pants. I was forced to tie a sweater around my waist in order to go on working. The worst was that even my boss asked me what I was doing with that sweater at my waist (Woman 5).

I stopped wearing skirts and dresses. I just wear long dark trousers, because when urine comes out, the color helps cover it (...) (Woman 18).

Avoiding coughing, sneezing and laughing

This is the use of strategies to contain urine leakage in situations when it is necessary to interrupt involuntary processes and perceived voluntary ones like coughing, sneezing and laughing.

(...) I cannot even have the flu, it's been a long time since I don't get the flu; when I have it, UI worsens (...) (Woman 5).

(...) I cannot run, cough and make efforts, because any movement that involves effort makes urine escape (Woman 6).

Abstaining from sexual activity

This means the decision to repress any approximation of the opposite gender, through the fear of the vexing situation of urinating during intercourse.

(...) I cannot find a mate (...) I'm glad he did not show up (...). Also, I have not gone to the Grandma Club (...) I cannot stand anymore! (...) At night, there's no time to get up to go to the bathroom, I have a bowl until I bought for urinating. I lost confidence in myself (...) (Woman 2).

DISCUSSION

By interrelating components (categories and subcategories) related to the experience of women who need to rely on palliative strategies when not seeing the possibility of UI improvement, in order to compare them and analyze them to understand how the interaction was between them, we realized moral and psychosocial vulnerability on the movement of this group, making them susceptible to health risks and, therefore, to compromising quality of life.

By analyzing the theme, imbricate to the theoretical model which was cut out, the component verified was *count on support and access to the rehabilitation process of UI* as a determinant able to break the moral challenge and psychosocial imposed by the disease and, therefore, preserving women's overload generated by the experience⁽²⁾.

The opposite occurred with the group of women who did not benefit from this determinant, and, therefore, were likely to experience an enhanced affective state by the awareness of the danger of being noticed with wet clothing or of exuding the odor of excretion, before other people. This process generated anxiety, fear and apprehension about a non-pleasant episode and that, in turn, disrupted life plans, promoting mental suffering, due to the continuous vulnerability of going through the embarrassment of violating a socially established precept: only children can urinate on clothes and wear diapers⁽²⁾.

This process can be interpreted through symbolic interactionism, which defines the human mind's action, which uses symbols and directs them towards the self. It is the individual trying to do something, to act in his world. It is the active communication with the self through the manipulation of symbols. The world is transformed into a multitude of definitions because of the mind; the action is response not to objects, but the active interpretation of the individual to these objects⁽⁹⁾.

Thereby, it is the symbolic interaction of the human being with his self and with others that leads the individual to make decisions that direct the course of actions. These are caused by an active process of decision making by the subject, which involves the definition of the situation that, in turn, involves interaction with oneself and with others. Thus, it is the definition of the situation by the woman that is central to how the action will occur⁽⁹⁾.

Interaction is not only what happens among people, but also what happens inside them. Humans act in a world that they define, act according to the way they define the situation experienced. Although this definition may be influenced by those with whom they interact, it is also the result of her own definition and interpretation of the situation⁽⁹⁾.

Urinating on clothes and using diapers is interpreted as a behavior not expected for adults and elderly and

UI exposes them to it. A person under such threat undertakes vexing movements, that is, driving her self to do something to manipulate this symbol, which propels women without perspectives of rehabilitation not to care about adopting strategies to contain urine, even though they may further compromise their health.

That interpretation, according to symbolic interactionism, corroborates the knowledge produced by others, which justifies the perpetuation of UI as a silent epidemic through the understanding that people have about the disease, from a social construct relativized by cultural factors, characteristically subjective and changeable, from an individual perception in a specific context of values, goals, expectations, standards and concerns. For such, they are under strong influence of conceptual models, in which physical and emotional functioning directly impacts on roles and social interaction in a collective dimension that surrounds everyday life⁽¹⁰⁾.

We further add that this conception has contributed for people to continue admitting UI as a normal problem occurring with aging or pregnancy, therefore being expected in groups of elderly and pregnant women, which slows the search for methods that mitigate or solve eventual alterations in bladder pattern⁽¹¹⁾.

Ethnic, social and cultural rights are associated with the divergence form of seeking help among women of several groups, because many individuals still stigmatize and marginalize those who have problems with UI⁽⁴⁾.

Those processes explain the reasons that lead UI to be considered an underestimated problem and, therefore, often overlooked by health professionals who should pay more attention to prevention, diagnosis and treatment of the disease⁽¹²⁾.

This context is not different in other countries, as demonstrated by a study conducted in the United States, in which the symptoms of UI are often perceived as a natural part of aging, both by health professionals and by people affected by it. Thereby, less than half of American women who suffer from UI seek treatment, and when seeking health care professionals due to several reasons, in most cases, they are not questioned about such symptoms, making the health problem invisible and thus generating a clinically significant proportion of the disease as undiagnosed⁽¹³⁾.

In Brazil, the gynecologist is still the health professional who investigates signs and symptoms of UI in women most often, as well as the one who has been indicating surgical treatment more often when compared to general practitioners and family physicians, who rarely investigate it or do not investigate it⁽¹⁴⁾. It is noteworthy that treatments to UI offered by SUS are surgical and medication, while physical therapy is, in most cases, provided only by private services or rehabilitation services at universities. This fact contradicts the principles that underlie SUS:

universality, equity and integrality. The lack of specific conservative programs for the care of women with UI is a fundamental problem, since they can contribute to improve part of the complaints of incontinent women and cure it⁽¹⁴⁾.

That process, in turn, ends up seriously impacting the quality of life of people affected when compared to unaffected ones⁽¹⁵⁾, making them susceptible to depression and panic disorder⁽⁷⁾, extending the impact to caregivers, family and health system, and to the provision of subsidies to the demands in different levels of care⁽¹⁶⁾.

Living with UI with no perspective of achieving rehabilitation leads one to modify behaviors in order to adapt to the inconvenience of urine leakage, using strategies that most often makes women susceptible to other physical, psychic and social complications.

Among those, need for gregariousness is affected, since women with UI start experiencing a more reclusive and lonely situation, due to their discontinuation of prolonged social, leisure and spiritual activities, attending only places with availability of toilets, and repressing needs related to sexuality in the face of insecurity and fear of urine leakage during sex. These situations cause them to urinate before intercourse or even to evade any interpersonal relationship with the opposite sex, to the point of not attending social spaces that enable encounters with a likely partner.

Social isolation has been identified by several studies as a consequence of UI^(12,17). It represents the border in which the individual does not engage fully, actively and equally in society, with a social and psychological function that causes considerable impact by loss of physiological autonomy, feelings of shame, depression, anxiety, stress and everyday social restrictions, among them receiving visits from friends and guests in one's own home⁽¹⁸⁾.

In this study, sexual abstinence was also found as a decision by women to restrain from embarrassing situations in front of the partner, a fact corroborated by other studies, showing that 26% of incontinent women report urine leakage accompanied by painful discomfort during intercourse (21%) and lack of pleasure (5%)⁽¹⁷⁾. Fear of urine leakage itself during intercourse was highlighted as a triggering factor for anxiety just by thinking about the act, leading them to consider their sexuality affected⁽¹⁹⁾.

Furthermore, women with UI using diuretics to treat hypertension were more likely to interrupt it, as well as to reduce fluid intake, especially when they had to leave home. This situation is corroborated by another study⁽¹²⁾ and considered alarming because it affects homeostasis of the human body.

Daily use of sleeping pills was also reported by women in this study, especially by those who started suffering from insomnia by foreseeing episodes of nocturnal enuresis.

It is known that one of the inconveniences of using sleep inducers is medium-term chemical and psychological addiction; therefore, in cases in which insomnia is configured as secondary to another base disorder, treatment is recommended⁽²⁰⁾.

Other women become worried about coughing and sneezing, for fear of not reaching the bathroom in time⁽²¹⁾; therefore, they try to suppress these physiological reflexes and even laughter as a preventive measure of urine leakage.

The limitations in work activities were also signaled as a limiting factor for professional and domestic performance⁽¹⁷⁾, because they force women with UI to stop their activities⁽¹⁹⁾, especially when they require physical effort^(1,15).

The use of urine collectors (tampons, cotton liners or diapers) is associated by women with their susceptibility to the onset of recurrent urinary and vaginal infections and to complications related to skin integrity.

The frequency of urinary tract infection (UTI) increases with age in both sexes and, in older women, in addition to menopause, anatomical and functional changes of the bladder related and unrelated to multiparity contribute to this increase⁽²²⁾.

Finally, the choice of clothes and frequency of exchanges is extremely important because it helps disguise when UI happens when the person is away from home. To this end, women seek to use dark clothes, do not wear skirts or dresses and wear outfits that can cover the visible sign of urine. Moreover, carrying extra clothing is always a possibility of providing more exchange.

CONCLUSION

In analyzing the findings of this study, it was found that the experience of the group of women with UI without the prospect of access to surgical treatment, after failed attempts with the conservative, not only faced the lack of clinical condition, but also the discrediting of medical professionals about the effectiveness of surgical treatment of UI in the life of those who recognized themselves in the conditions. It is understood that this context may be driving the group of women studied to moral and psychosocial vulnerability of an experience that creates overload, imposing a coping process, through palliative strategies, lest they be judged as transgressors of a socially established precept.

These strategies affect human needs within moral, spiritual, physical, psychic and social domains, processes that make them susceptible to physical and mental health risks and therefore risks to the quality of life.

This study raises new questions. If, after failure of conservative treatment, women in clinical conditions should

undergo surgery to correct the UI and the SUS offers this treatment, then why is one group of women being deprived of this possibility? What leads medical professionals to discredit the effectiveness of the treatment?

For this purpose, it is understood that one of the contributions of this research is to signal the need for conducting further studies, but with medical professionals, to give voice to them and to understand the conception which they carry of UI, as well as the entire existing rehabilitation process and thereby to deepen the understand-

ing of the barriers that may still be preventing women from having access to available treatments, especially surgery.

Finally, public policies would be required aimed at women's health, with more incisive interventions concerning the prevention and rehabilitation of UI, being incumbent on the professional educational bodies of health care professionals to provide competencies so they can contribute to resolution of a disease of great impact, especially in the lives of women.

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