PHYSICAL, EMOTIONAL, AND SOCIOECONOMIC REPERCUSSIONS IN INDIVIDUALS WHO EXPERIENCE THE PROLONGED WAITING FOR SURGERY

Repercussões físicas, emocionais e socioeconômicas nos indivíduos que vivenciam a espera prolongada por cirurgia

Repercusiones físicas, emocionales y socioeconómicas en individuos que experimentan la espera prolongada por la cirugía

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ABSTRACT: Objective: To describe the physical, emotional, and socioeconomic repercussions resulting from the prolonged waiting for surgery by users of the Brazilian Unified Health System (SUS). **Method:** Descriptive study with a qualitative approach, carried out based on the electronic database "Caixa Preta da Saúde". The registered records were collected in 2015. The results were presented in thematic categories and interpreted according to the Theory of Praxic Intervention of Nursing in Public Health. **Results:** The prolonged waiting for surgery contributed to: 1) the worsening of physical health, characterized mainly by pain and disability; 2) emotional suffering, evidenced by despair, indignation, frustration, among others; 3) the socioeconomic impact related to the inability to work and defray health expenses. **Conclusion:** The prolonged waiting for surgery had a negative impact on the lives of individuals. Comprehensive care in the care of patients who need surgery will be guaranteed if it is addressed in the structural, singular, and particular dimensions.

Keywords: Surgical procedures, operative. Health services accessibility. Nursing.

RESUMO: Objetivo: Descrever as repercussões físicas, emocionais e socioeconômicas decorrentes da espera prolongada por cirurgia pelos usuários do Sistema Único de Saúde. **Método:** Estudo descritivo, com abordagem qualitativa, realizado com base no banco de dados eletrônico "Caixa Preta da Saúde". Os registros cadastrados foram coletados em 2015. Os resultados foram apresentados em categorias temáticas e interpretados segundo a Teoria de Intervenção Práxica da Enfermagem em Saúde Coletiva. **Resultados:** A espera prolongada por cirurgia contribuiu para: 1) o agravamento da saúde física, caracterizado principalmente por dores e incapacidades; 2) o sofrimento emocional, constatado pelo desespero, indignação, frustração, entre outros; 3) o impacto socioeconômico relacionado à incapacidade para trabalhar e custear gastos com a saúde. **Conclusão:** Evidenciou-se que a prolongada espera por cirurgia impactou negativamente a vida dos indivíduos. Acredita-se que a integralidade do cuidado na assistência ao paciente que necessita de cirurgia será garantida se for abordada nas dimensões estrutural, singular e particular.

Palavras-chave: Procedimentos cirúrgicos operatórios. Acesso aos serviços de saúde. Enfermagem.

RESUMEN: Objetivo: Describir las repercusiones físicas, emocionales y socioeconómicas derivadas de la prolongada espera quirúrgica de los usuarios del Sistema Único de Salud. **Método:** Estudio descriptivo, con abordaje cualitativo, realizado mediante la base de datos electrónica "Caixa Preta da Saúde". Los registros fueron recolectados en 2015. Los resultados fueron presentados en categorías temáticas e interpretados de acuerdo a la Teoría de la Intervención Práxica de Enfermería en Salud Pública. **Resultados:** La espera prolongada para la cirugía contribuyó a: 1. Empeoramiento de la salud

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física, caracterizada principalmente por dolor y discapacidad; 2. Sufrimiento emocional verificado por desesperación, indignación, frustración, entre otros; 3. Impacto socioeconómico relacionado con la incapacidad para trabajar y los costes sanitarios. **Conclusión:** Se hizo evidente que la larga espera para la cirugía tuvo un impacto negativo en la vida de las personas. Se cree que la integralidad en la atención de los pacientes que requieren cirugía estará garantizada si se aborda en las dimensiones estructural, singular y particular.

Palabras clave: Procedimientos quirúrgicos operativos. Accesibilidad a los servicios de salud. Enfermería.

INTRODUCTION

Surgery is an indivisible and indispensable part of health care and can help millions of people lead healthy and productive lives. Thus, it must be a fundamental component of the national health system in all countries, regardless of their level of socioeconomic development.[1]

In the next 20 years, because of the epidemiological transition in many low- and middle-income countries, the need for surgery will continually and substantially increase.[1] Affordable and safe surgical care contributes to the reduction of morbidity and mortality, and disabilities resulting from surgical conditions. In addition, it improves the well-being of the population, economic productivity, individual capacity and freedom, contributing to the long-term development of countries and the strengthening of health systems.[1-4]

Despite the undeniable relevance of surgery in the context of public health in Brazil, in a survey conducted in 2014 to assess the opinion of Brazilians on health care, most respondents pointed out that surgery is one of the procedures most difficult to be accessed in health services. They also stated that the wait is too long and, for 29% of those in the queue, it can exceed six months.[5] In addition, waiting for treatment can be a factor that generates anxiety, stress, and uncertainty, interfering with daily social activities and affecting work capacity.[6]

In the indexed literature, this is the first study to address the physical, emotional, and socioeconomic repercussions of users of the Brazilian Unified Health System (SUS) who are waiting for surgery in southern Brazil. Seen that, given the global importance of surgical care, its impact on patients' quality of life, the limited access and the interest in answering some emerging challenges in Nursing, the present study is proposed.

OBJECTIVE

To describe the physical, emotional, and socioeconomic repercussions resulting from the prolonged waiting for surgery by users of the Brazilian Unified Health System (SUS).

METHOD

Documentary study, with a qualitative approach, carried out based on a secondary source of public domain data from the electronic database "Caixa Preta da Saúde". Created on March 12, 2014, the result of a non-governmental initiative of the Brazilian Medical Association (*Associação Médica Brasileira* - AMB), this database is an electronic communication channel with users of health services and aims to receive and compile complaints/records about problems affecting public and private health in Brazil.[7]

Through the electronic address http://www.caixapretadasaude.org.br/, anyone, from any location in the country, can register and send their complaint with the description of the event, selecting the city and the state.

Data collection was carried out collectively by two researchers in December 2015. In the electronic database, on the aforementioned website, a check box was available to select each state in the country. After this choice, the municipalities that had registered complaints were available for selection. With the selection of each municipality, text boxes were opened with the record of the complaint in full.

In the data collection process, the records of the period of one year were recovered from the creation of the electronic page. Therefore, it happened from March 2014 to February 2015, for each municipality in the Southern region of the country. The recovered records were separated by states and stored in Excel spreadsheets. In each of these, the following variables were filled out: date of the complaint, municipality, health service involved, complete description, relation with surgical care (yes or no), relation with the prolonged waiting time (yes or no). Each complaint was read in its entirety and those that met the following inclusion criteria were selected: the complaint should address the waiting for surgery and the repercussions resulting from this waiting on the individual's life.

In data analysis, two other researchers participated collectively in the process. The reports were grouped into thematic categories and analyzed qualitatively. For the codification of reports, the city of origin of the complaint and the waiting time for the surgery were mentioned.

In this study, the Theory of Praxic Intervention in Nursing in Collective Health (*Teoria de Intervenção Práxica da Enfermagem em Saúde Coletiva* - TIPESC) was chosen as the theoretical basis. Based on the materialistic, historical, and dialectical worldview, this theory is therefore born in the field of collective health and within the framework of the social determination of health-disease processes. It seeks to capture and interpret a phenomenon linked to the social production and reproduction processes related to the health-disease of a given community, within the framework of its conjuncture and structure, in a historically determined social context: the phenomenon of intervening in this reality and continuing to reinterpret objective reality to interpose again an intervention instrument.

There are three dimensions of objective reality in the operationalization of TIPESC: the structural, the particular, and the singular. The structural approach is the approximation of the macroscopic or macrostructural aspects of the focused object. The particular one refers to the epidemiological profile of the class, the reproductive profile, the health-disease profile, and health practices and ideologies. The singular highlights the processes that lead to falling ill or dying, or the development of the biopsychic nexus given by the individual's functioning and consumption-work pattern.[8]

The study complies with Resolution No. 466/2012 of the National Health Council, and the project was approved by the Ethics Committee, via Plataforma Brasil, under Certificate of Presentation for Ethical Appreciation (CAAE) No. 44899215.0.0000.0104 and opinion No. 1.124.424/2015.

RESULTS

According to data from Caixa Preta da Saúde, 3,773 complaints involving health care were registered and came from all regions of Brazil. In the Southern region, there were 462 complaints, of which 72 involved surgical care. Of these, most (n=51) mentioned difficulties in accessing surgery. In addition, there was a predominance of complaints (n=26) that reported physical repercussions, followed by those that addressed emotional repercussions (n=17), and eight that mentioned socioeconomic impacts. In most reports, patients were simultaneously affected by physical, emotional, and/or socioeconomic repercussions resulting from the situation of waiting for surgery, as shown in Table 1.

Next, the reports that involved the long wait for surgical care are categorized and presented in three categories.

Physical health worsening due to prolonged waiting for surgery

Regarding the reports, the prolonged waiting time contributed to the appearance of physical discomfort evidenced by pain, worsening of the pain or physical limitations of patients, preventing them from performing routine activities that were previously considered simple. There were also other symptoms reported, as shown in the following excerpts:

> *"Release of gallbladder surgery* [...] *only for September 29... I suffer constant pain"* (Cachoeira do Sul City/Rio Grande do Sul State, five months of waiting).

> *"I've been in line for tonsil surgery since 2010* [...], *I'm having pain in the back of my neck, which goes*

Table 1. Characterization of the complaints registered at Caixa Preta da Saúde, differentiated by states in the Southern region of Brazil.

Variables	Southern Region States			
	Paraná	Santa Catarina	Rio Grande do Sul	Total
Complaints topic				
General	185	89	188	462
Surgical care	35	16	21	72
Waiting for surgery	26	9	16	51
Repercussions due to prolonged waiting for surgery				
Physical	14	4	8	26
Emotional	7	4	6	17
Socioeconomic	5	1	2	8

through my neck and into my ear" (Londrina City / Paraná State, five years of waiting).

"She had a twisted femur that when she went to see it, was broken, but as she was weak from the bones, the doctors claimed that the surgery could not be done, so she has been like this for four years on a wheelchair" (Porto Alegre City / Rio Grande do Sul State, four years of waiting).

"Since 2008, I have been waiting for a surgery to remove materials from the elbow […] *, I feel a lot of pain"* (Joinville City / Santa Catarina State, six years of waiting).

"My father was admitted to the UPA […], *but until today he has not been able to find a vascular surgeon. He has a fever every day"* (Curitiba City / Paraná State, waiting time not mentioned).

"My father-in-law […] *has a 90% blockage of his carotid artery, compromising the vascularization of the brain, having to perform more a very urgent surgery* […], *until today the surgery has not been done, he has dizziness and loss of concatenation of ideas"* (Maringá City / Paraná State, eight months of waiting).

"My sister […] has *been waiting for bariatric surgery for over three years, she became blinded due to the complications of diabetes"* (Canoas City / Rio Grande do Sul State, three years of waiting).

Although the waiting time for care was not long, it put the patient at risk. Additionally, the wait for surgery was due to the lack of materials, as described below:

"Pregnant for three days with a dead baby in her belly, she is still waiting for a cesarean" (Rolândia City / Paraná State, three days of waiting).

"I have a kidney stone of 0.8 cm stopped in my ureter, I need a double J catheter placement surgery […], *I have to wait because there are no materials for the surgery, I feel constant cramps* […], *I run the risk of losing my left kidney functions"* (Londrina City / Paraná State, 20 days of waiting).

Physical health worsening due to prolonged waiting for surgery

In this category, feelings identified were despair, helplessness, psychological suffering, frustration, shame, feeling of disrespect, humiliation, neglect, disbelief, revolt against the SUS and the care provided by some professionals. Patients and their family members experienced prejudice and embarrassment:

"My aunt was diagnosed with a tumor in her leg bone and it's been over a year […], *I would like to ask for help, for the love of God"* (São João do Sul City / Santa Catarina State, more than a year of waiting).

"I've been waiting for surgery for seven years […], *I don't know what else to do"* (Curitiba City / Paraná State, seven years of waiting).

"I have hemorrhoids […], *after almost two years, they called me to book the surgery* […], *then they called me to cancel it because of a holiday* […]. *I found it disrespectful to me, I felt humiliated* […], *I came home frustrated, feeling ashamed of being Brazilian, a worker"* (Florianópolis City / Santa Catarina State, proctology, two years of waiting).

"I was referred for the placement of a knee prosthesis almost eight years ago and until now nothing […], *disregard with the Brazilian people!"* (Guaíba City / Rio Grande do Sul State, orthopedics, eight years of waiting).

"I have been waiting for vascular surgery on the lower limbs for five years […], *I am afraid of losing my legs. God help me! I paid* the *INSS* [National Social Security Institute] *all my life and now that I need it, they turn their back to me"* (Porto Alegre City / Rio Grande do Sul State, vascular, five years of waiting).

"I have been waiting for bariatric surgery for four years […], *not to mention the prejudice that all obese people face on a daily basis"* (Sapiranga City / Rio Grande do Sul State, four years of waiting).

In some cases, the waiting period evolved to more serious conditions, such as death. In these situations, the repercussions

were not restricted to the individual, but included close people and family members. In addition, according to the reports, there are situations in which there was negligence in the care, as shown in the following reports:

> *"I lost a friend, simply because doctors did not touch patients when assessing them; her appendix burst* […]*, she had to wait 13 hours for a surgery that should have been done urgently* […]*, she lost her life due to irresponsibility and delayed care"* (Rio Grande City / Rio Grande do Sul State, 13 hours).

> *"My father* […]*, 89 years old, was waiting* […] for *an appointment with a cardiologist, because he needed a pacemaker* […]*, unfortunately his heart couldn't take the wait"* (Viamão City / Rio Grande do Sul State, five months).

> *"My father needed to be seen in the emergency room* […] *because he had severe pain in his abdomen* […]*, they applied dolantine, a potent medicine for pain... There was an improvement in the pain and my father was released* […]*. When it was midnight (already Saturday) my father enters in the ER again with the same complaint* […]*, my father was left with no care of a professional until 4 pm* […]*. My mother was desperate* […]*. When they opened it, he had a perforated ulcer, the intestine was necrotic, a kidney no longer worked... Anyway... My father passed away"* (Guaíba City / Rio Grande do Sul State, 16 hours).

Socioeconomic impact due to prolonged waiting for surgery

In this category, the impossibility of working due to the worsening of physical health was a frequent complaint, according to the following narrations:

> *"I have been waiting for varicose vein surgery since August 2012* […]*, I am out of work, as I feel a lot of pain"* (Santa Maria City / Rio Grande do Sul State, three years of waiting).

> *"I ruptured the cruciate ligament on my left knee three years ago* […]*, I am unable to work"* (Almirante Tamandaré City / Paraná State, public, three years of waiting).

> *"I am waiting for the surgery until today* […]*, I can no longer work due to the hernia"* (Curitiba City / Paraná State, one year and six months of waiting).

> *"My mother has been in line for stomach reduction surgery for three years* […]*, she can't work anymore, and no news about the surgery"* (Londrina City / Paraná State, three years of waiting).

> *"My husband is awaiting knee surgery* […]*. He is away from work indefinitely"* (Londrina City / Paraná State, waiting time not mentioned).

> *"To do thyroid surgery, which is in an advanced state and penetrating the rib cage, there were 2,287 people in line* […]*, we will have to sell things (car, other objects) to pay for a private surgery"* (Foz do Iguaçu City / Paraná State, waiting time not mentioned).

DISCUSSION

The present study revealed that the long wait for surgery experienced by SUS users in the Southern region of Brazil had a wide and negative impact on the lives of individuals. In addition to the worsening of physical condition, emotional and social problems emerged from this unacceptable condition of waiting.

In a study conducted with a similar purpose, the authors showed that waiting for surgery involved a prolonged period of decreased health in the lives of individuals. In addition to physical condition, the psychological and social dimensions were affected. The variation in the severity of these consequences among patients indicates that prioritizing cases could reduce this personal burden resulting from waiting. Early information on the length of the delay can further promote patient acceptance for waiting.[6]

In an attempt to take a broader look at this issue and its contradictions, we must understand it and approach it from the structural, particular, and individual points of view, as it is believed that this phenomenon stems from the contradictions found in the interpretation of such a dramatic reality.

In an analysis from the structural point of view, the Brazilian Federal Constitution of 1988 is used, which puts health as a right for all and a duty of the State, guaranteed through social and economic policies to reduce the risk of disease and other conditions, and universal and egalitarian access to actions and services for their promotion, protection, and recovery. For the operationalization of health policy, SUS was created, with the purpose of offering the Brazilian population health services from primary to tertiary care, based on the following principles: universality, equity, and integrality.[9]

In view of the lack of access and guarantee of surgical care, evidenced by the results of this study, the current health policy, guided by solid principles, did not fulfill its purpose. One of the contributing factors is believed to be the historical and unacceptable underfunding, in addition to the inefficient management of the health sector in Brazil, with *per capita* public spending on health lower than in countries with universal systems just like ours.[7]

Among the services provided by SUS, surgical procedures are the second most requested. Consequently, 143.2 million reais (BRL) were allocated to elective surgeries in 2015, as regulated by ordinance No. 1,034, of the Ministry of Health.[10] However, governmental initiatives like this are important, but not resolving for those who experience the waiting situation. To overcome this macro-structural challenge, political will is needed to make health a government priority.

The delay in care led some users to declare that they had sought private health care. Thus, the mechanisms for installing private medicine as the main and non-supplementary system are strengthened, deepening the crisis in Brazilian public health. This crisis started in the post-1988 Federal Constitution as a normative contradiction, because, if on the one hand a legal system promises universal and unrestricted health, on the other, the reality of little concreteness of the citizenship right to health in Brazil is evident by its underfunding.[11]

Since it is estimated that 5 billion people do not have access to anesthetic and surgical care when needed, the Lancet Commission on Global Surgery was created in 2013 to assess the current state of worldwide surgical care and make concrete recommendations for universal access to anesthetic and surgical care. This commission established the performance of 5,000 surgical procedures per year for 100,000 people by 2030. This indicator corresponds to an adequate supply of the needs in anesthetic and surgical care. To achieve this goal, ensuring a wide expansion of health and surgical systems will be imperative, which implies hiring twice the surgical workforce by 2030. This expansion of the surgical volume must be accompanied by an increase in quality, safety, and equity, which must be guaranteed by local managers in the countries.[12]

In the particular dimension, many access failures are revealed due to poor management of health services. The organizational causes related to health institutions are lack of beds and professionals, scheduling errors and communication failures, as well as administrative problems of another nature.[13] As an example of this, in a study conducted to investigate the number of elective surgeries canceled in a university hospital and to identify its causes, the authors pointed out that, for three months, 1,699 elective surgeries were scheduled, of which 466 (27.4%) were canceled. Most cancellations occurred "at the surgeon's discretion", which was found in 264 cases (56.7%), without specifying the reason for the decision.[14]

During the period prior to the surgery, individuals remained unattended by health services and professionals, which was demonstrated in the reports characterized by insecurity, fear, revolt, and disbelief in relation to these services. This lack of care and complete absence of a bond between individuals and health professionals largely violates the principle of integrality. This reality is not exclusive to Brazil, as verified in a study carried out in Canada, which showed that patients waiting for bariatric surgery did not receive care in the period prior to the procedure. The researchers suggest that the health system should provide a contact person who could provide information about the waiting time, the place on the waiting list, and explanations of the delays.[15]

This gap in care for patients in the waiting phase, for those who need surgery, leads us to primary care, since it is the user's gateway to SUS for later referral to the specialized service.[16] In this study, the results revealed the existence of care demands on individuals, either to minimize problems arising from the pathological process, or to prevent the occurrence of other psychosocial disorders arising from the waiting situation. It is therefore suggested that, in the scope of basic and specialized care, there has been negligence in care. In this regard, Nursing, in the care of patients with surgical needs, can act in a relevant way outside the Surgical Center/Hospital. This is because nurses, in primary and secondary care, have

a fundamental role in this process and can be leaders in preventive care actions to problems arising from waiting for surgery and, thus, strengthen the health care of those who wait for the procedure.

In England, a strategy considered successful in managing waiting is the definition of the minimum time recommended and established time for different types of elective procedures, and the association of hospital incentives or penalties for fulfilling this objective. Moreover, other interventions to reduce the long waiting list are screening actions which can be performed, that is, prioritizing cases taking into account the severity of the disease, the benefit that the surgical procedure would bring, and the possibility or not of working in a clinical way with that patient.[17]

In the singular context, these citizens are in a state of vulnerability, weakened in guaranteeing their rights as citizens. The prolonged wait can evolve to worsen the health-disease process, resulting from the space of social production, characterized by inequities and lack of care.[18] Besides that, impaired physical and emotional conditions prevented professional functions from being performed, functions that are not only a source of livelihood, but also of status and part of personal identity.

Therefore, the social determination of health in the dilemma of waiting for surgery is notorious, because of the following social contradictions: lack of access to surgery and lack of care in other levels of care to prevent physical and psychosocial problems resulting from prolonged waiting for surgery. This reveals the invisibility of care actions, even of nurses, in this useful field for their performance and for exercising the role of Nursing.

As a limitation, this study covered the dilemmas arising from patients who experienced prolonged waiting for surgery in southern Brazil and who were registered voluntarily in the database consulted. Therefore, this reality may not be representative for the entire country.

Despite this, this investigation provided an opportunity to learn about the situation of health service users waiting for surgery, in the three dimensions of objective reality. In the structural dimension, the issue was analyzed from the perspective of the governmental role of the State and its contradictions: health as a constitutional guarantee and health policy with solid foundations and principles, but which is not widely guaranteed to citizens. As it is not a government priority, the State is deserting its role in guaranteeing it. In the particular dimension, the reorganization of health services must provide comprehensive health care at all levels of care. However, the contradiction is evident in the inefficient management and the lack of care promoted by health services and professionals. In the singular dimension, the following contradiction stands out: individuals have health needs that go beyond the scope of the pathological process that generated it, because they are unassisted, and other problems and demands for care arise in the physical, mental, and social aspects.

Regarding the implications for Nursing, these results act as a call to nurses at all levels of health care, given that surgical patients are in different points of the care network and, therefore, must be fully cared for strengthening the health system and the current health policy.

FINAL CONSIDERATIONS

The main repercussions resulting from the wait for surgery experienced by individuals first covered the physical aspects, characterized mainly by pain and physical disability, and other physiological changes. The following emotional repercussions were found: despair, indignation, frustration, neglect, prejudice, and embarrassment. In the socioeconomic implications, the following stood out: inability to work and defray excessive spending on the private health sector. The patients who used the Caixa Preta da Saúde e-mail address did so in an outburst tone, mentioning only the negative aspects that waiting for a surgical procedure brought about in their lives, regardless of the nature of these impacts.

The reports carry wide discontent and dissatisfaction with the current situation of SUS in Brazil. There were no reports revealing positive experiences with the service or the performance of professionals during the waiting period. When telling their personal story or that of a family member or friend, individuals had the opportunity to expose their fears and concerns regarding health, in the expectation that the scheduling of the surgery would be streamlined. This shows that this individual misfortune, in essence, is collective, involving family members, friends, services, health professionals, and the State.

In conclusion, the long wait for surgery is a multifactorial problem. Comprehensive care in patient care that requires surgery can only be guaranteed when it is understood and addressed in all its dimensions.

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