DOI: https://doi.org/10.36489/saudecoletiva.2020v10i56p3198-3213

Institutional racism from the perspective of care ethics in health services: an integrative review

Racismo institucional desde la perspectiva de la ética del cuidado en los servicios de salud: una revisión integradora O racismo institucional sob a perspectiva da ética do cuidado, nos serviços de saúde: revisão integrativa

ABSTRACT

The aim of this study was to analyze, in national and international literature, institutional racism in health services from the perspective of ethics considering that ethical problems are challenges that have several courses of action for their solution or management, requiring deliberation and consideration in order to find the best path, which in turn, needs to be continually reassessed. The integrative review was chosen as the method based on the guiding question: What is the scientific evidence on institutional racism in health services? The search was carried out at the Virtual Health Library and at the Scopus base. From the survey carried out, the study corpus consisted of 15 studies. The analysis resulted in three thematic categories: Approach to the definition of Institutional Racism, Barriers to accessing health services and Disparities in morbidity and mortality rates. Ethics in care comes to support our functions and responsibilities towards clients. When we reflect on the way we are carrying out the care and the consequences of our actions on patients, we start to value all our actions, from the smallest acts to the great actions. **DESCRIPTORS:** Ethics: Racism: Health Services.

RESUMEN

El objetivo de este estudio fue analizar, en la literatura nacional e internacional, el racismo institucional en los servicios de salud desde la perspectiva de la ética considerando que los problemas éticos son desafíos que tienen varios cursos de acción para su solución o manejo, requiriendo deliberación y consideración para encontrar el mejor camino, que a su vez, debe reevaluarse continuamente. Se eligió la revisión integradora como método basado en la pregunta orientadora: ¿Cuál es la evidencia científica sobre el racismo institucional en los servicios de salud? La búsqueda se realizó en la Biblioteca Virtual en Salud y en la base Scopus. De la encuesta realizada, el corpus de estudio estuvo conformado por 15 estudios. El análisis resultó en tres categorías temáticas: Aproximación a la definición de Racismo Institucional, Barreras para acceder a los servicios de salud y Disparidades en las tasas de morbilidad y mortalidad. La ética en el cuidado viene a respaldar nuestras funciones y responsabilidades hacia los clientes. Cuando reflexionamos sobre la forma en que estamos llevando a cabo los cuidados y las consecuencias de nuestras acciones en los pacientes, comenzamos a valorar todas nuestras acciones, desde los actos más pequeños hasta las grandes acciones. **DESCRIPTORES:** Ética; Racismo; Servicios de Salud.

RESUMO

Objetivou-se analisar, em literatura nacional e internacional, o racismo institucional nos serviços de saúde sob o olhar da ética considerando que problemas éticos são desafios que contam com vários cursos de ação para sua solução ou manejo, exigindo deliberação e ponderação a fim de encontrar o melhor caminho, o qual por sua vez, necessita ser continuamente reavaliado. Optou-se como método a revisão integrativa a partir da questão norteadora: Quais as evidências científicas sobre o racismo institucional nos serviços de saúde? A busca foi realizada na Biblioteca Virtual em Saúde e na base Scopus. A partir do levantamento realizado, o corpus do estudo foi constituído por 15 estudos. A análise resultou em três categorias temáticas: Abordagem da definição de Racismo Institucional, Barreiras no acesso a serviços de saúde e Disparidades nos índices de morbimortalidade. A ética no cuidado vem para fundamentar nossas funções e responsabilidades diante dos clientes. Ao refletirmos sobre a forma como estamos realizando os cuidados e as consequências de nossos atos sobre os pacientes, passamos a dar valor a todos os nossos atos, desde os menores atos até as grandes ações.

DESCRITORES: Ética; Racismo; Serviços de Saúde.

RECEIVED ON: 03/16/2020 **APPROVED ON:** 03/16/2020

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INTRODUCTION

n view of the diversity of color / race and cultures in different countries, it is necessary to recognize the health needs of individuals and family members of different population groups in a given territory, which, in turn, must be taken as an object of health practices., so that these are operationalized in response to the needs that originated them, in a circularity between health needs and health work. Health needs are not restricted to medical needs, health services, or health problems, but concern the shortages or vulnerabilities that express ways of life and identities.

For an adequate analysis of the social conditions and health of the population, it is still necessary to consider the serious and insistent issue of racism, persistent even after a series of institutional conquests, due to its high degree of strangeness in Brazilian culture. Racism is reaffirmed on a daily basis by common language, it is maintained and nourished by tradition and culture, it influences life, the functioning of institutions, organizations and also the relationships between people; it is a historical condition and brings with it prejudice and discrimination, affecting the black population of all social strata⁽¹⁾.

From an institutional point of view - which involves policies, programs and interpersonal relationships - institutions must be considered to compromise their performance when they fail to offer a qualified service to people due to their ethnic-racial origin, skin color or culture. This commitment is the result of institutional racism. Institutional racism is the systematic production of ethnic-racial segregation in institutional processes. It manifests itself through discriminatory norms, practices and behaviors adopted in daily work, resulting from ignorance, lack of attention, prejudices or racist stereotypes. In any case, it always puts people from discriminated racial or ethnic groups at a disadvantage in accessing benefits generated by the action of institutions and organizations⁽¹⁾.

Thinking of organizing the fight against institutional racism, two dimensions are created, the first is that of interpersonal relationships, the second is programmatic politics, the two being treated in an interdependent manner. The interpersonal relationship dimension is characterized by the relationships that are established between managers and servers, between the servers themselves and between the servers and the users of the services.

The programmatic political dimension is characterized by the production and dissemination of information about different and / or unequal experiences in being born, living, becoming ill and dying; for the ability to recognize racism as one of the determinants of inequalities in the process of expanding individual potential; by investing in specific actions and programs to identify discriminatory practices; for the possibilities of elaborating and implementing mechanisms and strategies for non-discrimination, combating and preventing racism and related intolerances - including the awareness and training of professionals; for its commitment to prioritize the formulation and implementation of mechanisms and strategies to reduce disparities and promote equity⁽¹⁾.

The aim of this study was to analyze, in national and international literature. institutional racism in health services from the perspective of ethics, considering that ethical problems are challenges that have several courses of action for their solution or management, requiring deliberation and consideration to in order to find the best path, which, in turn, needs to be continually reassessed. Ethical problems cannot be solved with ready-made recipes, but they require permanent creativity, in order to open new alternative solutions, with a view to ethical excellence in the practice of health care services⁽²⁾.

Health ethics tried to balance principles, such as beneficence, autonomy, and justice to address dilemmas; as such, health disparities have been a factor of social justice. The transformation of health care proposes to reformulate this lens, adding that to address the disparities, it is not only necessary to talk about social justice, but also about ethical issues. Care centered on the patient / user requires knowledge of cultural competence and the ethics of care.

METHODOLOGY

An integrative review was chosen as a method, a specific method that summarizes the past of empirical or theoretical literature, to provide a more comprehensive understanding of a particular phenomenon⁽³⁾. The integrative review allows the synthesis of studies already published, allowing the generation of new knowledge based on results presented by research. This methodology also contributes to determine the current knowledge on a specific theme, since it is conducted in order to identify, analyze and synthesize results of independent studies on the same subject, thus contributing to a possible beneficial impact on the quality of care that is provided to the patient⁽⁴⁾.

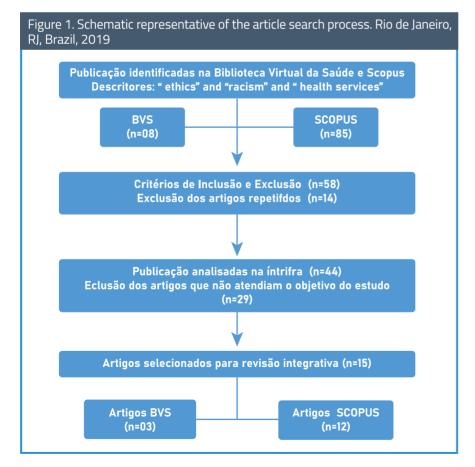
Six steps were taken to develop the review: the first step was the definition of the guiding question of the research, in the second step the inclusion and exclusion criteria were defined, in the third step the databases were chosen and the search for scientific productions was carried out , in the fourth step the data analysis was carried out, in the fifth step the data discussion was developed and in the sixth step the synthesis of the review was presented⁽⁴⁾.

The guiding question of the study was: "What is the scientific evidence on institutional racism in health services?". To answer this question, an online search was conducted in the databases: available in the Virtual Health Library (VHL) and in the Scopus database.

The inclusion criteria used were: articles available in full, free online, national and international productions, with health services as the study setting. Exclusion criteria: theses, dissertations, monographs, repetition in databases and articles that, after reading, do not converge with the object of study. The time space was not limited to identify the largest possible number of studies produced with this theme.

The study data search was carried out between September and November 2019. This study is part of the construction of a doctoral research project and had the participation of the doctoral student, the advisor and co-supervisor. The descriptors used were: "Ethics AND Racism AND Health Services".

After reading 29 articles in full, 14



were excluded for different reasons, which only cited the issue of institutional racism in the health system and focused on the discussion in areas such as education and public safety. The study consists of the 15 selected articles, which were integrated into the review.

Through thematic or categorical analysis type of content analysis technique⁽⁵⁾, The text was broken down into units (categories), according to systematic analogical groupings. The analysis of message content should be applicable to all forms of communication, as it has two functions that may or may not dissociate when put into practice. The first says that content analysis enriches the exploratory attempt and increases the propensity for discovery. The second refers to the administration of the evidence, in which hypotheses, in the form of questions or provisional statements, serve as guidelines appealing to the method of analyzing a confirmation or information⁽⁵⁾.

Bardin⁽⁵⁾ signals three steps for content analysis. Pre-analysis is the first, which consists of the organization of all materials that will be used for data collection, as well as other materials that can help to better understand the phenomenon and fix what the author defines as the corpus of investigation, which would be the specification of the field that the researcher should focus.

The analytical description is the second stage, in which the collected material that constitutes the research corpus is more in-depth, being guided in principle by the hypotheses and the theoretical framework, resulting from frames of reference, looking for coincident and divergent syntheses of ideas. The third step, and no less important, is the referential interpretation, the analysis phase itself.

The content analysis does not obey the rigid stage, but rather a simultaneous reconstruction with the researcher's perceptions with possible ways that are not always clearly marked out.

RESULTS AND DISCUSSION

From the survey carried out and described above, the corpus of the study will consist of 15 studies, which are presented in Chart 1 below.

In the analysis of the 15 articles selected for review, some points were highlighted. One of these points is that only one article was built in Brazil, in 2007, which demonstrates that the theme of institutional racism related to ethical issues in health services has not yet been widely discussed among Brazilian researchers.

According to the publications by year, the studies were distributed as follows: 2002 (1), 2006 (1), 2007 (4), 2008 (2), 2009 (2), 2012 (1), 2013 (1), 2014 (2) and 2015 (1), more than 50% of them were published in the last ten years.

Approach to the definition of institutional racism

"It is racism that exists in a systemic and institutional way, where the production, control and access to resources works for the benefit of selected racial / cultural groups and harms others⁽⁶⁾."

"Institutional racism is defined as the "collective failure of an organization to provide an appropriate and professional service to people because of their color, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviors that total discrimination due to involuntary prejudice, ignorance, neglect and racist stereo-

typing, which causes disadvantages to people of ethnic minority⁽⁷⁾."

Of the 15 articles selected, only three addressed the definition of institutional racism. An Australian article produced in 2012 and two articles published in 2007, one in Brazil and the other in England.

In the 1960s, the fight for civil rights in the United States, the fight against apartheid in South Africa and the end of colonialism in African and Asian countries represented profound changes in studies on racism in the world. It was recognized that institutions, administrative practices and political and social structures could act in an adverse and racially discriminatory or exclusive manner. The concept of racism has been expanded to co-

Chart 1. Articles selected according to the chronology of publications, title, journal, method and country of origin of the research. Rio de Janeiro, RJ, Brazil, 2019

research. Rio de Janeiro, RJ, Brazil, 2019				
ANO	τίτυιο	PERIÓDICO	MÉTODO	PÁIS
2002	Race and Healthcare Disparities: Overcoming Vulnerability	Theoretical Medicine	Revisão	EUA
2006	Disparities in Pain: Ethical Issues	Ethics Forum	Revisão	EUA
2007	Racismo Institucional: um desafio para a equidade no SUS?	Saúde e Sociedade	Estudo exploratório	Brasil
2007	Institutional racism in mental health care	BMJ	Estudo de Reflexão	Inglaterra
2007	American Indian Women, HIV/AIDS, and Health Disparity	Informa Health Care	Estudo de Reflexão	EUA
2007	Telling Stories: nurses, politics and aboriginal Australians, circa 1900 and 1980s.	Contemporane Nurse	Pesquisa Documental	Austrália
2008	The Neglect of Racism as an Ethical Issue in Health Care	J Immigrant Minority Health	Revisão	Austrália
2008	Disparity vs Inequity: Toward Reconceptualization of Pain Tre- atment Disparities	Pain Medicine	Revisão	EUA
2009	Racism and inequalities in health: notes towards an agenda for critical health psychology	Journal of Health Psychology	Estudo de Reflexão	Nova Zelândia
2009	Harms and benefits: Collecting ethnicity data in a clinical context	Social Science & Me- dicine	Pesquisa Etnográfica	Canadá
2012	Reducing the health disparities of Indigenous Australians: time to change focus	BMC Health Services Research	Pesquisa de campo	Austrália
2013	Public health genomics: a new space for a dialogue on racism through Community Based Participatory Research	Public Health	Editorial	EUA
2014	Understanding Inequalities in Access to Health Care Services for Aboriginal People A Call for Nursing Action	Advances in Nursing Science	Pesquisa de campo	Canadá
2014	Addressing Disparities and Achieving Equity Cultural Compe- tence, Ethics, and Health-care Transformation	CHEST	Pesquisa de campo	EUA
2015	Unconscious Race and Social Class Bias Among Acute Care Surgical Clinicians and Clinical Treatment Decisions.	JAMA Surg.	Estudo de Reflexão	EUA

ver forms of institutional racism and structural racism. Racism came to be identified as a situation that could occur regardless of people's will, recognizing that certain practices, carried out by institutions, have no attitudes, but they can certainly discriminate, create obstacles, prevent and harm the interests of a group because of your race, your color⁽⁹⁾.

Stokely Carmichael and Charles V. Hamilton, two militants of the American black movement, present the distinction between individual and structural (institutional) racism in the book "Black Power: the politics of liberation", 1967. For the authors, individual racism presents in an open and associated way with individuals, and the structural (institutional) in another way, undeclared and institutional, "it is the collective failure of an organization to provide an appropriate and professional service to people because of its color, culture or ethnic origin ". The important thing about this analysis is that it starts to dissociate racism from acts and intentions or from the conscience of some actors⁽⁹⁾.

Racism is a crucial device of power historically exercised to disaggregate and subject peoples, classes, ethnicities, and races. Blacks suffer not only this racial segregation conducive to racial prejudice and operated at the private level, but above all institutional racism, which transmits and materializes in the state policies directed at them. It is a racial distinction exercised by States when exercising differently in relation to these population segments, crossing in our cities and society, in the direction of public policies, an opening between what must remain alive and what must perish. Among the forms of racism there is institutional racism⁽¹⁰⁾.

Against these considerations, in 2013, Werneck⁽¹¹⁾ defined institutional racism as "a way of subordinating law and democracy to the needs of ra-

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cism, making the former none or exist in a precarious way, in the face of barriers interposed in the experience of groups and individuals imprisoned by the latter's subordination schemes".

In health organizations, institutional racism is perceived in policies that disregard the different types of diseases and deaths between whites and blacks; in the development of professionals where the debate on racial issues is not included; for indifference in attention and treatment, among other tenuous ways such as dumbness and looks. The involvement of professionals in the fight against racism in health institutions is of great importance and is based on ethical principles⁽⁷⁾.

The practice of institutional racism in health predominantly affects black and indigenous populations. The invisibility of the diseases that are most prevalent in these population groups, the non-inclusion of the racial issue in the training apparatus, the difficulty of accessing health services, the quality of health care, as well as access to inputs, determines important differences in profiles of illness and death among whites and blacks⁽⁶⁾.

Health care ethics, by their very nature, involve values, views and propositions that invite and provoke controversy. Ethical issues such as abortion, euthanasia, end-of-life decision-making, reproductive technology, genetic engineering, to name a few, are all familiar topics of debate and disagreement between health professionals in literature. A less familiar topic in health care ethics, however, is that of racism. Just because racism as a theme of care ethics has been overlooked.

Barriers to accessing health services

Kalckman⁽⁷⁾, in Institutional Racism: a challenge for equity in SUS? They emphasize that institutional racism in Brazil affects mainly the population of blacks and Indians. The study showed that in times of fragility such as childbirth and prenatal care, situations of discrimination are more frequent.

> "[...] the difficulty of access to health services, the quality of health care, as well as access to inputs, determines important differences in the profiles of illness and death between whites and blacks" ⁽⁷⁾.

Thompson and Durey⁽⁶⁾ address the health disparities experienced by the aboriginal population, discuss how racism provides this group of the population with collective experiences, memory of abuse, insensitivity and are more likely to suffer discrimination in health services.

According to Cameron⁽¹²⁾, stories of racism, stigmatization, harassment and fear were described by the participants in their research as factors considered as barriers to accessing health services. Participants also described that medical care needs such as laboratory tests and consultations with specialists were not problems / barriers, but interaction with health professionals and the technical vocabulary used often.

Study⁽¹²⁾ reported experiences of access to an emergency service, by aborigines and non-aborigines. What stood out from this work was the significance of personal and social health care experiences that have previously influenced the indigenous people's access to emergency services. Clear reports from study participants show that access to care will primarily include overcoming inhibitions against demand. It also reports that the participants clearly state that access to care primarily includes overcoming inhibitions against seeking care due to the negative experiences in the past that influenced access to care. This makes it relevant to understand the disparity and inequality in access to health care

that many Aboriginal individuals have experienced in Canada.

According to Kalckman⁽⁷⁾, the report of a 32-year-old black nurse, associates skin color with low purchasing power, seeming to be increasingly common and constant:

"The receptionist was slow to pay attention to me and when I handed over the health insurance card, she looked at me twice, asked for my ID, something she had not done with other white patients, she didn't seem to believe that I could pay the health insurance. They treat us like a second-rate being, even the request for an identity document, can be interpreted as 'taking the real proof' is that person really benefiting from this plan?".

Participants described that, as previous experiences with health services had been negative, there was no encouragement to develop a relationship of trust with professionals. Access continues to be insufficient, because the link between local control of services and health practices is not given due attention⁽¹²⁾.

The population, many times, sees institutional racism in health services as an interpersonal posture, however, its presentation in these cases is systemic and institutional, as there is the production of control and access to resources, placing certain racial groups in advantage. This structure of privileges increases inequities in terms of access, hurting the right of this population to adequate information and equitable treatment.

Equal access to health services is significant for reducing inequalities and barriers to accessing health services. However, aboriginal, indigenous, and black individuals experience this experience with reports of difficulty and / or limited access to these services. Access, according to the Health Law, defines the equitable distribution of services to the disadvantaged for the common good and health for the entire population, this access to health is not merely linked to the service provided to that individual in general, but also how this service arrives at the service location. Bearing in mind that this access is a watershed in terms of the social determinant of health⁽¹²⁾.

However, not all Canadians make use of this equal access to health services. There is a persistent inequality in the state and access to health services for the Aboriginal population, configuring a concern in the way they face the barriers to achieve equitable entry⁽¹²⁾.

This has been a long journey, however, the relevance generated regarding those engaged in this work with many partners is evidenced, in order to awaken a more humanized and more sensitive health system, for this less favored population that supports inequality, making an appeal ethical and political decision making of this Aboriginal people regarding this gap⁽¹²⁾.

Disparities in morbidity and mortality rates

Studies have long demonstrated that there is a profile of racial inequalities in access to health services that has the serious consequence of a disparity in the morbidity and mortality data of some situations such as, the prevalent diseases in the population not being treated as a public health problem or the high rates of maternal and child mortality in this group.

Stephens and Christine⁽¹³⁾ report that there is a group of indigenous people with very poor health status in Australia. The life expectancy of the indigenous population is 17 years less than that of Australian whites; infant mortality is 3 times higher; death rates for Australian Indians, across all age groups, are twice as high. "[...] lower survival rate among black patients with early stage small-stage lung cancer compared to white patients⁽¹⁴⁾."

"A significant number of studies show that black patients experience greater chances of death after trauma compared to white patients⁽¹⁵⁾".

According to Rafael, cited by Cameron⁽¹²⁾, Indigenous peoples still suffer from a disease burden, such as the onset of chronic illness and disability at younger ages than their non-indigenous counterparts.

The author also reports that access to health services addresses not only the ability of individuals or communities to receive assistance from essential services, but also how these services are made available at the place of care⁽¹²⁾.

According to reports by Smedley, Stith and Nelson in 1986, cited by Vernon⁽¹⁶⁾, according to data from the Control and Prevention Center (CDC), from 1986 to 2001, women represented only 7% of AIDS cases across the country, in 2000 they now represent 17% of cases. The disease alert increases with respect to the ethnic population, especially among ethnic women. The Census Bureau, 2001 - US, reports that in the United States, the ethnic population is made up of a minority of approximately 24.9%, however they correspond to 58% of SIDA cases found according to the 2001 CDC. popular belief that says the AIDS crisis is decreasing, this infection is growing rapidly mainly among women of color, where ethnic women are made up of 29% (less than a third) of all women in the United States, however, according to the 2001 CDC, it represents 79% of the female community colonized by AIDS⁽¹⁶⁾.

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Since the arrival of the colonizers. indigenous peoples have suffered abuse, forced labor, confinement and sedentarization. A very suggestive number of these people ends up disappearing due to the colonization process, where the practices of slavery, slaughter, wars, and epidemics by infectious diseases were more evident.

and sedentarization. A very suggestive number of these people ends up disappearing due to the colonization process, where the practices of slavery, slaughter, wars, and epidemics by infectious diseases were more evident. Therefore, the author states that indigenous peoples have always suffered from this mark of prejudice and disregard for the Brazilian State⁽¹⁷⁾.

Measures that can bring about a resolution to health disparities should be carried out from the top down, from the bottom up, and from the middle in both directions. Following IOM's suggestion, starting with laws and policies, one way is through existing civil rights. In addition, formal policies that propose inherent measures to eliminate disparities that encompass these vulnerable groups could be implemented by hospital accreditation agencies. And in order to reduce health disparities more effectively, there is a need for specific laws and regulations with requirements from the health system and managed care organizations⁽¹⁸⁾.

The National Policy for Integral Health of the Black Population (PN-SIPN), as well as the National Policy for the Attention to Health of Indigenous Peoples (PNASPI), builds a management model that integrates all ethnic groups in society with the right to health through the promotion of health, attention and health care, giving priority to reducing ethnic-racial inequalities, combating racism and discrimination in the organizations and services of the Unified Health System. In view of the above, it is worth emphasizing the importance of adequate assistance to this population due to the time of discrimination suffered. Health is a right of everyone and essentially of those people who are in the most vulnerable areas of the communities. The author concludes that knowledge of Health Policies that have access to health actions and services for all is of paramount importance⁽¹⁹⁾.

CONCLUSION

Different studies show that populations that are considered "minorities", from the point of view of access and rights in health services, have been suffering from situations of racism, discrimination and prejudice in different health devices and in their different degrees of complexity.

In view of this reality, there is an urgent and urgent need to foster discussions in Brazil that go beyond the unveiling of existing inequities in the health system in an effective way, that will collaborate in understanding how these situations happen and how these disparities influence / act in the health of the black population.

Another point of paramount im-

portance to improve the tracking and (re) knowledge of these inequities is to decentralize research in a way that takes into account the continental dimension of our country and the territorial capillarity that provides us with a great ethnic-racial diversity, with the addition of regional particularities.

Institutional racism present in health services can be classified as unethical by its very nature, as it involves values that provoke controversy. Both the issue of equity and the strategy of treating unequal people in an unequal way, respecting their specificities, and it is not possible to measure the consequences of equity practices.

The ethics of care understands that the ability to act ethically is an "active virtue"

that needs two feelings: the first is the natural feeling of care and the second when there are responses to the memory of the first, since each individual brings with them a remembering the moments when you have cared or been cared for and if you wish, you can access it, as it directs your conduct. There are times when caring is shown to be completely natural, without imposing ethical conflicts, since both "wanting" and "duty" coincide.

In short, ethics in care comes to support our functions and responsibilities towards customers. When we reflect on the way we are carrying out the care and the consequences of our actions on patients, we start to value all our actions, from the smallest acts to the great actions.

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