

Realizing the Right to Health of Persons With Disabilities in Africa: “Empowering Health Professionals for Quality Care of Persons With Disability. A Case of Rwandan Public and Private Health Caregivers”

Josephine Mukabera, Jane Umutoni
University of Rwanda, Kigali, Rwanda

Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. In this context, health professionals should be able to provide quality care in line with the needs of people with disability. This paper examines how Rwandan health professionals are empowered in terms of knowledge and equipment related to delivering quality care to people with visual, hearing, and speech impairment. This paper is framed around the capacity building theory. The study used a qualitative approach through semi-structured interviews with health professions from selected health institutions located in different provinces across Rwanda. The objective was to explore existing gaps in terms of capacities, facilities, challenges experienced by the health professionals as well as strategies for better service delivery to people with disabilities. Findings revealed strategic plans of the Rwandan health sector related to removing barriers that prevent people with disabilities to access health services are not accompanied by effective practice. Key factors that contribute to poor services delivery to people with disability included lack of knowledge and skills (85.5%), insufficient equipment and facilities (61.5%), absence of supportive partnerships (96%), financial constraints and negative attitudes from families and communities members. Hence, there is a necessity of joint efforts between key institutions including Ministry of Health, Ministry of Education, National Council of Persons with Disabilities and other key stakeholders in mainstreaming disability throughout programs and projects. Additionally there is a need to promote training initiatives related to disability as well as providing clinics and hospitals with necessary equipment required for quality care to patients with disability. Furthermore, these practical efforts need to be supported by close monitoring systems. Lastly community education is crucial in promoting inclusive communication among community members both those with and without disabilities in all social settings.

Keywords: Rwanda, empowerment, health professionals, impairment, disability, quality care and service

Josephine Mukabera, Ph.D. in Interdisciplinary Gender Studies, lecturer & researcher at the Centre for Gender Studies, University of Rwanda, Kigali, Rwanda.

Jane Umutoni, MSocSci in Gender and Development, assistant lecturer/researcher at the Centre for Gender Studies, University of Rwanda, Kigali, Rwanda.

Introductory Background

Achieving healthy lives and promoting wellbeing for all at all ages is part of the focus of the 2030 Agenda for Sustainable Development (United Nations, 2015). Globally, social factors like ethnicity, gender, and disability often intensify the experience of health disparities (Manandhar et al., 2018). Arguably, Bueno de Mesquita et al. (2018) explain that a better understanding of factors contributing to access to health services will inform policy makers and support the achievement of other Sustainable Development Goals such as attaining gender equality, reducing poverty, and improving education. In that context, efforts to build the capacity necessary to achieve sustainable health conditions through providing quality medical services accessible to the most vulnerable groups are made by social institutions and NGOs. Basically, physical and cognitive impairments, and persistent illnesses exacerbate vulnerabilities (Grosse et al., 2006). Therefore, access to adequate care and appropriate rehabilitation services is needed to mitigate the effects of those vulnerable conditions. Generally, quality health care is defined as “the extent to which health care services provided to individuals improve desired health outcomes (World Health Organization, Organization for Economic Co-operation and Development, and The World Bank, 2018).

With respect to equity, inclusiveness, and respect of human rights, the health of vulnerable social groups such as those having special needs caused by their illnesses, impairments, and disabilities need to be given more attention. Hence, this study was done in the context of the 2020 annual conference on disability rights in Africa organized by the Centre for Human Rights of the University of Pretoria/South Africa. The conference aims to critically appraise policies, practices, and programs that impede the respect, protection, and fulfilment of the right to health of persons with disabilities. Through the lenses of a capacity building framework, the paper focuses on exploring how health professionals are empowered to be able to deliver quality care to people with hearing, visual, and speech impairments. Although the terms “impairment” and “disability” are interchangeably used in this paper, Barbotte, Guillemin, Chau, and the Lorhandicap Group define impairment as “any temporary or permanent loss or abnormality of a body structure or function, disturbing functions that are essentially mental or sensory, or affecting internal organs or external parts of the body” (2001, p. 1047). Some of chronic health conditions indicating impairment are visual disturbances or hearing problems. In line with this, disability is “a restriction or inability to perform an activity in the manner or within the range considered normal for a human being, mostly resulting from impairment” (Barbotte et al., 2001, p. 1047). Persons with disabilities or disabled people refer to persons with impairments or health conditions who are deprived in wellbeing (Mitra, 2018). Finally, empowering health professionals relates to giving them required knowledge, skills, and resources through education and professional training that increase their abilities to skillfully care for disabled patients and adapt to changes throughout professional relationships (Porter-O’Grady, 2003). Linking the above views with the topic of this paper, ensuring quality healthcare to people with impairments requires that health professionals know their specific conditions and needs well, are able to communicate with them, and can provide them with effective information and care that responds to their actual health condition.

Rationale for the Study

The Universal Declaration of Human Rights highlights the necessity for every human being without discrimination to enjoy medical care and necessary social services¹.

Recognizing the right to health as a discrete human right, the Convention on the Rights of Persons with Disabilities affirms that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.²

Globally, skilled health professionals are needed to provide appropriate health services to disabled patients and mitigate the effects of disability on their wellbeing. However, studies have shown that one of the main barriers that prevent disabled people to access quality health care is that health providers often fail to provide responsive services to them due to lack of adequate knowledge, skills, and equipments (United Nations, 2006; World Health Organization and The World Bank, 2011).

In the context of Rwanda, the Government of Rwanda has signed international and regional agreements, in particular the Universal Declaration of Human Rights and the United Nations Convention on Persons with Disabilities. Rwanda has committed to mainstream disabilities in key National Development Programs from 2010 to 2019 (Republic of Rwanda, 2014). Hence, the rights of persons with disabilities are protected along with all other Rwandan citizens by the Constitution and the National Law No. 01/2007 on the Protection of Persons with Disabilities (Republic of Rwanda, 2015a). Fundamentally, disability is recognized in the Rwandan strategic plans of the education and health sector (Thomas, 2005). Thus, the Rwanda Health Sector Policy promotes a community development marked by the provision of equitable, accessible and quality health care services, thereby enhancing the general well-being of the population. Particularly, the health sector focuses on developing interventions that address social, gender, and economic barriers to improve social protections for vulnerable/marginalized individuals with respect to Universal Health Coverage (Republic of Rwanda, 2015b). In teaching and training health workers, the capacity development focuses on improving the quality and increasing the quantity of human resource for health, and to strengthen the health professional bodies and teaching institutions. Finally, the health sector strives to promote the social inclusion of disabled people through removing barriers that prevent them to access health services (Ministry of Health, Republic of Rwanda, 2018).

¹ Universal Declaration of Human Rights (1948), Article 15: “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control”.

² Convention on the Rights of Persons with Disabilities (CRPD), Article 25: States Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs;

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

(c) Provide these health services as close as possible to people’s own communities, including in rural areas;

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

In Rwanda, people with disability numbered 154,236 in 2016 (Republic of Rwanda, 2016). However, the Rwanda National Council for People with Disability (NCPD) revealed that the Rwandan health system does not seem to meet the needs of persons with disabilities, which can vary considerably according to the type of impairment or severity of disability; moreover disability is not even taken into account because health care professionals do not know how to deal with it (Republic of Rwanda, 2014). Practically, many health professionals lack communication skills necessary to communicate with patients suffering from visual, hearing, and speech impairment. Additionally, many persons with impairments are usually unable to communicate with sign language specialists who are supposed to help them to explain their conditions to medical staff (Mukabera & Umutoni, 2019). Moreover, individuals trained in sign language who usually help disabled people are few and not available in almost all health centres. Furthermore, patients who cannot speak and hear are not trained in sign language too. This usually results into distorted communication or misunderstanding between health professionals and patients, reluctance to seek treatment by patients, and discrimination of patients by professionals, thereby worsening the health condition of disabled persons. As noted by Smith, people with disabilities were more likely than non-disabled people to think that their doctor did not listened to them, treated them with respect, taken enough time, or explained treatment properly (Smith, 2009). For this reason, Baker et al. underscored the necessity of ensuring training and education about disability for health professionals due to their negative attitudes and lack of knowledge to provide quality services to disabled people (Baker, 2011). Arguably, Kirschner and Curry point out the necessity for health professionals to be trained in assessing the consequences of disability on the health and how to interact with people with disabilities (Kirschner & Curry, 2009). The authors further stress the importance of learning about the patient-centred care approaches, as well as the understanding of legal frameworks related to the Rights of Persons with Disabilities.

For patients, using a third person such as a sign language interpreter reduces the effective communication between them and health professionals which will impact on how the patient will communicate his/her health issue as well as apply medical advice thereafter thus affecting the healing process in general. For this reason, health professionals should have knowledge on disability conditions and communication skills that help them to understand issues experienced by disabled people and provide appropriate and relevant care. In order to provide a good service to people with disability, NCPD finds relevant to train medical professionals on specific health care and assistance needs of persons with disabilities (Republic of Rwanda, 2014).

Although Rwanda reflects a political will to implement disability legislation, Thomas observed that policies and strategic plans have not translated into available and accessible services for persons with disabilities. In addition, there were limited services for persons with intellectual, mental, and sensory (hearing and visual) impairments (Thomas, 2005). NCPD argues that despite obvious willingness of many structures and organizations, little is known on how to go about disability-related issues (Republic of Rwanda, 2014). To promote a just and sustainable society, monitoring the close link between development objectives of providing equitable and quality health care services for all and their effective implementation requires regular studies that inform law and policy makers, as well as development practitioners. Therefore, the general objective of this paper is to explore the extent to which health professionals are empowered to enable them to deliver quality care to people with disabilities in Rwanda. Specifically, the paper assesses the abilities of health professionals and available facilities to address the health needs of people with hearing, visual, and speech impairments; it further

explores challenges experienced in providing care to people with visual, hearing, and speech disabilities; and potential strategies to improve health services provided to this group.

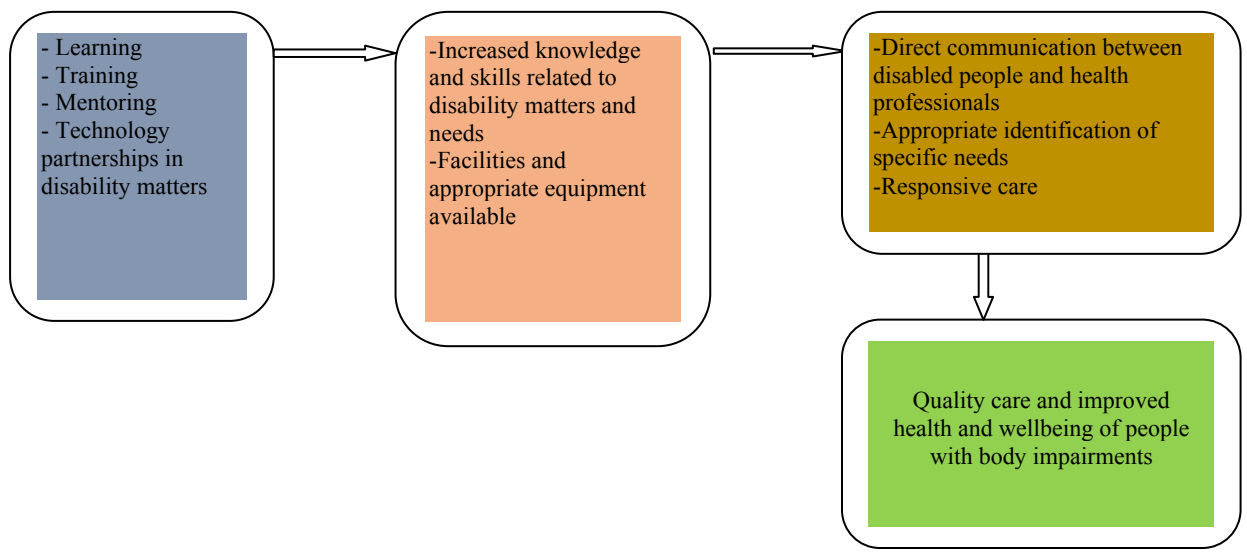
This study generated relevant information on the gaps and challenges faced by health professionals in caring for disabled patients, which will inform health and development practitioners in their future planning and practices that will promote effective change and outcomes in caring for people with disabilities.

Capacity Building and Empowerment of Health Professionals for Quality Care of Disabled People

Capacity is defined as the ability of individuals and organizations to perform functions effectively, efficiently, and sustainably (UNDP Capacity Development Practice Note, 2008). For Horton, Alexaki, and Bennet-Lartey (2003), capacity building is an ongoing process by which individuals (in this case health professionals: doctors, nurses, social workers) increase their ability to perform core functions, and understand and deal with the development needs in a sustainable manner. In terms of community empowerment, capacity building is the process by which people gain knowledge, skills, and confidence to improve their own lives (Rifkin, 2003). Therefore, capacity building is characterized by improving skills, resources, and management at the individual and organizations (Andriana, 2012). Likewise, Rwanda NCPD highlights that “equipping people with the necessary skills and qualifications is a key prerequisite for full inclusion in society” (Republic of Rwanda, 2014).

With regard to the capacity category, this study focuses on the resources capacity which relates to building the capacity of health professionals to promote quality care (Horton, Alexaki, & Bennet-Lartey, 2003). It specifically concerns skills and equipments needed by health professionals to better serve disabled people. The measures of capacity building taken into consideration are developing skills through structured learning, continuous improvement through training and mentoring; practical guidelines to improve quality and access, applying electronic-based knowledge exchange, as well as partnership strengthening sharing expertise for the benefit of quality care for people with disability (Robins, 2007).

Conceptual Framework



Methodology

Research Design and Approach

The current study is a qualitative appraisal that seeks to understand the experiences of health professionals in delivering services and care to people with disabilities in Rwanda. Specifically, the study places emphasis on care provided to individuals with hearing, visual, and speech impairments mostly needing a third person to explain their suffering to medical staff.

The study is an in-depth qualitative research case study of Rwanda health caregivers conducted through interviews on their knowledge, skills, and resources they have to enable them to provide care to patients with body impairments. As presented above, this research is conceptualised through the concept of capability taking into consideration skills developed through learning, training, mentoring, applying electronic-based knowledge exchange, as well as sharing expertise through establishing partnerships with the aim of providing quality care to people with disability. The study provides a lens through which poor or insufficient care to people with disabilities can be seen as a result of poor or insufficient knowledge and skills acquired during the professional development of health professionals as well as on the job training. Likewise, lack of necessary equipment and facilities contributes to delivery of quality care and service to people with disabilities.

Sample design and analysis. The study data were collected from 12 purposively sampled health institutions across the country based on the specific services they offer as well as their location in different provinces of Rwanda namely: City of Kigali (Central), Northern, Southern, Eastern & Western provinces.

As additional criteria, the sample size mixed rural and urban health institutions as well as private and public ones as displayed in Table 1.

Table 1

Health Institutions, Their Status and Location

No.	Hospitals/health centres	Province	District	Public	Private	Urban	Rural
1	Butare University Hospital	South	Huye	Public		Urban	
2	Polyclinique la Medicale	South	Polyclinique la Medicale	Private	Private	Urban	
3	Kaduha District Hospital	South	Nyamagabe	Public			Rural
4	Kabgayi District Hospital	South	Muhanga	Public		Urban	
5	Gisenyi Health Centre	West	Rubavu	Public		Urban	
6	Kintobo Health Centre	West	Nyabihu	Public			Rural
7	Kibagabaga District Hospital	City of Kigali	Gasabo	Public		Urban	
8	Beri Clinic	City of Kigali	Gasabo	Private	Private	Urban	
9	Nyamata Hospital	East	Bugesera	Public			Rural
10	Gahini District Hospital	East	Kayonza	Public	Public		Rural
11	Gahini Rehabilitation Center	East	Kayonza	Private	Private		Rural
12	Hospital Kinihira	North	Rulindo	Public			Rural
Total	12			9	3	6	6

Data were collected using a qualitative approach through semi-structured interviews with purposively selected health professionals per health institution visited. At each location, participants included medical staff based on their positions that obliged regular interaction with patients. Hence, the study collected views

from social workers who receive and orient patients to the department relevant to their health problems, doctors who to whom patients go for consultation, and nurses who provide prescribed care and advice as well as specialists who conduct specialized exams or care (i.e., X-ray technician, physiotherapists). In total, 26 health professionals were interviewed including 11 nurses, seven doctors, two physiotherapists, five social workers, one x-ray technician. Respondents include 20 females and six males. All respondents were aged between 25 and 55 age range. Data collection for this study was conducted between 21st and 30th October 2020.

Key areas explored during the interviews included types of disabilities treated, available skills in disability matters, relevant training received, equipment and facilities available, existing relevant partnerships, challenges and barriers faced, and possible strategies to improve care and service to people with disabilities.

Data Analysis

The analysis of data used quantitative descriptive tables to present results as well as a qualitative thematic analysis that aligns results to the study objectives. Rossman explains that some key steps followed in data analysis are organizing the data, identifying categories and generating themes, coding, interpretation, searching for alternative understanding, and writing report (Rossman & Rallis, 2017). These steps were respected in the analysis of results from the present study based on the questions asked and the responses received. The data analysis compared data from private health institutions and those provided by public ones in relation to training opportunities, facilities as well as challenges experienced by health professionals in their efforts to care for patients with disabilities.

Ethical Considerations

The study observed and respected all set research and data collection ethics and protocols. Clearance to conduct field research was approved by the Directorate of Research and Innovation at University of Rwanda, College of Arts and Social Sciences (UR-CASS) before data collection as per set procedures. Additionally, participants gave their consent to voluntarily participate in the study in addition to assurance of respect for confidentiality during and after the interviews by the research team. All references are detailed in footnote as recommended in the PULP guidelines.

Results Presentation and Discussion

Presentation of Results

The general objective of this paper was to explore how Rwandan health professionals are empowered in terms of knowledge and equipments related to delivering quality care and challenges they face in delivering services to people with visual, hearing, and speech impairment as presented below.

Knowledge and skills. With regards to knowledge and skills of health professionals that enable them to deliver specific services related to the health needs of people with hearing, visual, and speech impairments, the results of this study showed 88.5% of the medical staff interviewed had no professional knowledge and/or skills related to helping people with the above mentioned impairments. Only three doctors among the respondents divulged that they had knowledge and skills related to physical therapy management, audiometry, and speech therapy.

Equipment and facilities. Regarding equipment and facilities, 61.5% of respondents pointed out that their institutions had no particular facilities or equipment related to speech, visual, and hearing impairment such as hearing aids, eye glasses, and assistive listening devices or other material helping persons with disabilities. 23.1% of the respondents acknowledged the availability of wheelchairs which were for general use but not specifically for people with disabilities. Nonetheless, one respondent revealed that he had visual aids such as alphabetical letters and images. Additionally, 41.1% of respondents underscored the fact that most equipment and facilities linked to providing service to people with disability are usually quite expensive and not easily affordable to some health service providers.

Existing partnerships and collaboration. In relation to existing partnerships, 96% respondents stated that they were not aware of any partnership in the area of disability, while only 4% showed that they had established partnerships with institutions that specialize in health services and care to people with disabilities.

Challenges faced by health professionals. Concerning challenges that prevent health professionals from giving appropriate services and care to persons with disability, 80.7% of respondents pointed out that they lacked knowledge and skills as well as training opportunity that would enable them to effectively deliver services to people with disabilities. Lack of communication skills such as use of sign language was highlighted as one of the key barriers to all respondents. It was also revealed that the majority of patients have no sign language skills too. Lastly, a few respondents highlighted the role played by the negative mindset of caregivers which includes the stigma by families and community members as well as financial constraints.

Lastly, with regards to how the respondents rate their institutions' confidence in skills, facilities to be able to address the health needs of persons with disability, 57.5% chose "not confident" while 42.5% felt themselves "confident" despite the obstacles of unavailable skills, equipment, and facilities as earlier explained.

Clearly, the above results exhibited no significant difference among the chosen institutions in terms of available expertise in the area of disability, available knowledge, skills in the same area as well as the available facilities and equipment. Whether urban or rural, private or public, the gaps identified the inability to provide quality and efficient service and care was more or less similar across.

Proposed strategies. Respondents proposed potential strategies to improve health services provided to persons with disability. These include equipping health professionals with knowledge/skills in disability matters through education and training; health should be equipped health institutions with adequate facilities and equipment; recruitment of health professionals with specialization in the area of disabilities and promotion of inter-professional partnerships and networks for mutual support.

Discussion of Results, Conclusion, and Recommendations

Based on the results above, it is evident that many Rwandan health professionals lack knowledge, skills, and equipment to be able to provide quality care to people with visual, hearing, and speech impairment. This gap is caused by the fact that matters related to disabilities may not be well mainstreamed in both formal and informal educational programs for health professionals as well as other training initiatives in general. Basically, the incapability to effectively communicate with patients having visual, hearing, and speech impairment can affect service delivery and care starting from the reception, consultation down to treatment and follow up. These findings conform with the observation of the World Health Organization and The World Bank (2011) revealing

that one of the main barriers that prevent disabled people to access quality health care is that health service providers often fail to provide responsive services to them due to the lack of adequate knowledge, skills, and equipments. Fundamentally, sign language should be considered as a crosscutting issue not only by medical professionals but also from primary school level where language skills are taught and learnt. Importantly, there is a necessity of teaching disabled individuals to use the sign language.

As disability is recognized in the Rwandan strategic plans of both the education and health sectors, strategic projects meant to translate planning into practice need to be implemented by all development practitioners from public and private health institutions to CSOs that intervene in providing equipments and capacity building.

In a recent study conducted in 2019 related to fighting GBV for girls and women with disability, it was observed that the majority of respondents were unable to communicate with sign language specialists who were supporting the data collection team (Mukabera & Umutoni, 2019). Considering that the Rwandan health sector strives to remove barriers that prevent disabled people to access health services (Republic of Rwanda, 2014), prioritization of capacity building is urgent for Rwandan medical staff in order to promote quality care to people with disability. Hence, there is a necessity of joint efforts between key institutions including Ministry of Health, Ministry of Education, National Council of Persons with Disabilities, and other key stakeholders in mainstreaming disability throughout programs and projects. Additionally there is a need to promote training initiatives related to disability as well as providing clinics and hospitals with necessary equipment required for quality care to patients with disability. Furthermore, these practical efforts need to be supported by close monitoring systems. Lastly community education is crucial in promoting inclusive communication among community members both those with and without disabilities in all social settings. Further, quality regulations governing private hospitals and health centres should give priority to necessary equipment and staff training to ensure that their services are more disability friendly and inclusive.

Baker et al. explain that ensuring training and education about disability for health professionals may work on their negative attitudes and lack of knowledge to provide quality services to disabled people (Baker, 2011). Moreover, health professionals need specifically to be trained in assessing the consequences of disability on health, how to interact with people with disabilities, the patient-centred care approaches, and the understanding of the legal framework related to the Rights of Persons with Disabilities (Kirschner & Curry, 2009). Further, promoting electronic-based knowledge exchange, as well as partnership may help health staff to develop their expertise for the benefit of quality care for (Robins, 2007). To conclude, good strategic development policies need to be supported by an appropriate monitoring system that closely follow up their effective translation into practice.

From the above perspectives, future researchers may assess the success and challenges of education of people with visual, hearing, and speech impairments to see how teachers are working to provide quality education to this group. Also, social researchers should assess the activities in place to empower disabled people to be able to express themselves. Lastly, there is a necessity for close collaboration between health institutions and CSOs working in social development, as well as a need for equitable allocation of available financial resources by Ministry of Health and in addition to prioritizing and responding to special needs of people with severe visual, hearing, and speech impairments.

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