

Voices of six mothers of children with Developmental Disabilities: experiences with health care workers in Gaborone, Botswana

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Abstract- The purpose of the study was to explore the experiences of mothers of children who live with developmental disabilities with reference to medical health care practitioners. Qualitative research approaches were used to explore the experiences of three mothers of children with Cerebral Palsy and three mothers of children with Autism Spectrum Disorder. Convenience sampling was used to select the study participants. A thematic approach was used to analyse the stories. The women's stories revealed that there is inadequate understanding of Cerebral Palsy and Autism by both the general public and health care workers. The lack of understanding of developmental disabilities impacts on the health and development of these children and over-burdens the mothers/caregivers. The mothers of children with developmental disabilities find themselves confronted by a condition they have to learn about while dealing with it and with very limited resources. In addition, the study revealed endurance and agency of these mothers as they continuously polish the gem they see in their children despite their status and stigma of living with disabilities. In conclusion, understanding of developmental disabilities in general by the general public and health practitioners would lead to improvement in the lives of those who live with such disabilities.

Keywords- Developmental disabilities, mothers, experiences, agency.

Definition of developmental disability/intellectual disability

Developmental Disability is an umbrella term that includes intellectual disability but also includes other disabilities that are apparent during childhood. The words; intellectual disabilities and developmental

disabilities are used interchangeably in this study. Developmental disabilities are severe chronic infirmities that can be cognitive, physical or both. The disabilities appear before the age of twenty-two and are likely to be lifelong. Some developmental disabilities are largely physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes a physical and intellectual disability, for example Down syndrome or foetal alcohol syndrome and other developmental disabilities often co-occur, intellectual disability professionals often work with people who have both types of disabilities. Adapted from,

<https://aaid.org/intellectual-disability/definition/faqs-on-intellectual-disability#.WhvsaFWWw71>

Introduction

The following quote by the former U.S. Secretary of Health and Human services in closing the Gap summed up the situation of persons with developmental disabilities in some parts of the world; *Compared with other populations, adults, adolescents and children with intellectual disabilities experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care... many health care providers and institutional sources of care avoid patients with this condition. Without direct clinical experience, health care providers may feel incapable of providing adequate care. They may not value people with intellectual disabilities....* (Kuntz, Garcin, Lewis, Mines, Martins & Holden, 2005 p. 58).

Health care systems play a critical role in ensuring quality health care services to the general population. To a large extent, mothers depend on the

advice and education on child care they receive during prenatal and postnatal lessons from the health care workers. One of the main goals of these sessions is to ensure the wellbeing of both mothers and babies; thus enabling them to fulfil their mothering role. The ideal postnatal care training should include: emergency preparedness and complication readiness for the mother and baby. Based on this, accessing the health care systems is associated with hope for solutions of wellness. However, observation is that no one prepares mothers and families to care for children with disabilities in Botswana. The mothers face a double challenge of learning of the situation they are confronted by and at the same time being primary caregivers. This situation is often worse where resources are limited. Observation is that not much is known about developmental disabilities by both the general public and the health care workers. As such mothers of children with developmental disabilities and their children are bound to experience insufficient assistance characterized by discriminatory attitudes. As reflected in the former U.S secretary of Health and Human services' words, persons with disabilities at some point in their lives, face prejudice and negligence. This discrimination against children with disabilities perpetuates the struggles of this marginalized population and continuously widens the gap between them and their non-disabled peers.

This study therefore, aims to explore the experiences of six mothers of children with developmental disabilities in regard to treatment they receive from health care workers in Gaborone and Bokaa in Botswana. In addition, the study establishes the mothers coping strategies.

Prevalence of disability in Botswana

About 15% of the world population is people living with disabilities, and 80% of this group lives in Sub Saharan Africa. The results from the 2011 Population and Housing Census show that, of the total Botswana population of about 2 million people, 59,103 (2.92 %) were reported to be people with disabilities (Central statistics, 2011). This is almost equal to the 2001 prevalence rate of 2.99 %. Based on the analysis of the 2011 Population and Housing Census data, the findings revealed that there has not

been significant change in the national prevalence rate of disability between 2001 and 2011 census, as the prevalence is still around 3.0% for both males and females. The most common type of disability reported was visual impairment (49%) followed by hearing impairment (20%). Disability is more prevalent in rural areas than in urban areas. This is consistent with previous censuses and world trends (Mmatli, Kebotsamang & Lesetedi,(2011). The data further showed that people with disabilities were more likely to have never been to school. Not much was found on access to health care systems, hence the study's main objective to find out what the experiences of mothers/caregivers of children with developmental disabilities are with specific reference to medical health practitioners.

Literature

There is evidence of prevalence of disparities and inequities that characterize the health outcomes of people living with disabilities in general. For example, literature, (Groce, 2014; World Health Organization, 2007) shows that interrelated factors that include socio-cultural, attitudinal and economic factors contribute to the marginalization of children with developmental disabilities in society. In addition, Krahn, Walker and Correa- De-Araujo, (2015) argue that the existing health disparities among people living with disabilities and their "non-disabled" peers are avoidable. For example, it has been noted that in certain cultures babies born with disabilities were not valued, and were often hidden to avoid the shame they would bring to their parents, while in other cultures they are considered to be a curse or a sign of the wrath of God to the family. These discriminatory cultural attitudes are also transmitted to society in general through folklore, books, films or television programmes (Innocenti research Digest, 2007). In modern times, the existence of deep-seated negative attitudes has been observed to play a major role in perpetuating the marginalization of children living with developmental/intellectual disabilities and disability in general.

Different models of approach aimed at improving people with disabilities' lives have evolved from the medical model where for a long time; children with disabilities were treated as objects of charity and passive recipients of welfare (Groce &

Kett, 2013). Often, conditions at the institutions (that prevailed with the medical model) were disheartening. This charity-based legacy persisted in many countries and to some extent it still affects the perception and treatment received by children with disabilities. Along with the Convention on the Rights of Children (CRC), the Convention on the Rights of Persons with Disabilities (CRPD), adopted by the United Nations General Assembly in December 2006, brought a new agenda of hope that aims to promote the human rights of all children with disabilities. Leeder and Dominello, (2005) noted that though a lot has been achieved in health at a global level, there is still persistence of inequalities especially with regard to the health and welfare of persons with intellectual disabilities.

Studies show that people with intellectual disability generally experience poor health than the general population (World Health Organization, 2011 Report; Beagne & Durvasula, 1999). People living with intellectual disability are often associated with lower life expectancy and less morbidity because not much is known about them. This same population is mostly at risk of obesity and respiratory related complications (Beagne, 1996). In addition dental disease has been found to be rife among people with intellectual disabilities and other conditions which are dealt with accordingly on persons with no disabilities (Beagne, Lennox & Parmeter, 1999 in Leeder & Dominello, 2005).

Findings from Krahn, Hammond and Turner's (2006) study revealed a cascade of health disparities experienced by this particular group. These include higher prevalence of adverse conditions, inadequate access to quality health services, inadequate attention to care needs as well as inadequate focus on health promotion in all societies and these compromise the enjoyment of their rights (World Health Organisation, 2011). The fact that they are already not counted for in most programmes, they are often left out on health campaigns such as breast cancer screening, cervical cancer and others. Beagne and Durvasula (2001) add that breast cancer deaths occur three times more commonly among women with cerebral palsy than any other.

Another observation is that people living with intellectual disability are often left out even in campaigns against any global epidemic of whatever nature especially in health. In another study Beagne, Lennox and Parmeter (1999) state that what is apparent with 'non-disabled' children often goes unnoticed with persons with intellectual disabilities. For example, even though children with intellectual disabilities are more vulnerable to HIV and AIDS infections, rape and unplanned pregnancies, they are often left out on campaigns on issues pertaining to sexualities. Groce (2013) made an observation that there are various myths and stereotypes about people with disabilities, several myths related to disability include the assumption that people with disability are asexual, and do not need sex education. Such assumptions influence the lack of services and programmes on HIV for people with disabilities. Groce (2013) argued that the stigma associated with disability has led to people avoiding the issue of HIV and AIDS because it creates double stigmatization due to both disability and HIV and AIDS.

In another study, Leeder and Dominello (2005) pointed that despite the large general gains in global health, the gains have not been spread evenly. This unevenness is underpinned by inequalities in the society. It has been observed that one of the greatest impediments in the general health and well-being of persons with intellectual disabilities is the long standing stigma, societal discrimination and negative attitudes that arise from misconceptions, stereotypes and attitudes that link disability with punishment for past sins, misfortune and witchcraft. Arguably, this has even permeated the health practice institutions. Given that health care workers are to a large extent expected or hoped to provide solutions to 'all health problems', it is disheartening to experience this perpetual health disparities and inequities in relation to people with intellectual disabilities.

Moyle, Iacono and Liddel (2010) carried out a study on knowledge and perceptions of graduate medical practitioners in Malaysia of their role in medical care of people with developmental disabilities. Their study indicated deficit and inconsistencies in both content and experience. The study concluded that there is need for increased content, training and exposure in relation to

developmental disabilities in all settings of undergraduate medical training.

Summing up, the literature reviewed revealed that the problems associated with poor health outcomes of people with developmental disabilities are at most linked to lack of knowledge and understanding of developmental disabilities and discriminatory attitudes by health care practitioners. Krahn, Hammond and Turner's (2005) study revealed this dearth of information as a global phenomenon. For example, Moyle, Iacono & Liddell (2010) linked the poor health outcomes of people with intellectual disabilities/developmental disabilities to lack of knowledge and experience with this population by medical practitioners.

Theoretical frameworks

The theory of intersectionality is based on the concept that oppressive institutions within a society, such as racism, ageism, ableism, sexism and homophobia do not act independently, but are instead interrelated and continuously shaped by one another (Joseph, 2015). Intersectionality framework was coined by the feminist scholar Crenshaw and its proponents argue that it can be used to understand systemic injustices and social inequalities. On women, it stipulates that women suffer from diverse discriminations due to several factors such as gender, age, class, disability and others.

Intersectionality is a tool that can guide researchers, policy makers and practitioners to learn about and respond to the diverse experiences of mothers of children living with disabilities and the social structures and systems that often exclude and silence them. Persons with disabilities (and their caregivers) are often viewed as the recipients of support and the beneficiaries of social programs rather than recognized as experts essential to the development of inclusive programs and policies. Even when consultation with experts occurs, the implementation of programs and policy may misrepresent them. The authentic representation of complex experience, the influence of intersecting social factors like gender, age, sexuality, culture and the true extent of the inaccessibility of resources and opportunities are most often still missing (Kudsen 2006). Using intersectionality can result in practices

and processes that are progressive, more socially just, and consistent with the needs of those living with disabilities (Knudsen, 2006).

Purpose

The purpose of the study was to explore experiences of children with Developmental disabilities (CP & autism) in the hands of medical practitioners through the voices of their mothers. The aim of the study is to give a voice to this marginalised population and create a platform for their stories to be heard.

Research Questions

The study answered the following questions:

1. What are the experiences of children with Intellectual Disabilities (cerebral palsy & autistic disorder) in the hands of medical practitioners in Botswana?
2. How do the mothers of these children mould the gem they see in their children despite their experiences and challenges?

Research Methodology

This qualitative study is phenomenological in nature because it is based on real life experiences; it depicts typical situations, daily experiences or occurrences and encounters of the participants with medical practitioners (McMilan & Schumacher, 2014; Giorgi & Giorgi, 2003).

Study participants

Six mothers were sampled using convenience sampling; three were mothers of children with Cerebral palsy and three were mothers of Autistic children. Four of the participants live in Gaborone while two lived in Bokaa village in Kgatleng District

Instruments

Focus group discussions, autobiographies and one-on- one in-depth interviews were used to collect the mother's stories. One- on-one interviews lasted for approximately 45 minutes each depending on the willingness of the participant to talk.

Ethical Considerations

Relevant steps that have to do with research with human subjects were taken. The purpose of the study was explained to the participants and issues of confidentiality were observed. Pseudonyms are used to protect the participants in the study. Participants

were asked to be free to ask for clarification of anything they would want to know or understand about the study. They were also made aware that they can withdraw from the study at any point if ever they felt like withdrawing. As a way of further protecting participants, the author used anonymity even in acknowledging the participants. Prior to the start of the data collection, two meetings were held to explain the purpose of research and consent forms were filled by the participants.

Data analysis

After every interview session, data was transcribed verbatim. We repeatedly listened to the audio tapes and read the transcriptions to familiarize with the women's narratives (Creswell, 2007). Data was analysed according to themes as they emerged from the data collected.

Results

From the autobiographies, group discussions and in- depth interviews conducted with participants, it was apparent that people living with developmental disabilities face challenges in accessing medical health care due to various reasons. Below are the themes that emerged from the mothers' narratives: late diagnosis, lack of understanding of the disability, attitude to disabilities, being insensitive and lack of counselling. The mothers' stories also revealed resilience, agency and strength in each other's support.

Late diagnosis

Generally participants indicated late diagnosis of their children's conditions by the medical practitioners. From the participants' stories, it is clear that the conditions of cerebral palsy and autism are not well known or researched even by medical practitioners such that mothers get frustrated at first by the problems they see their children displaying especially that they fail to get professional help quickly. This is what Mma K echoed about her son with cerebral palsy:

I was a young mother when I gave birth to my two boys. One of the twins, seemed weak. He made sounds when breathing such that you could hear him if you were standing just by the door where he was. Each time he cried with a very loud voice as if he was in excruciating pain. Several times I took him to the

hospital, the health practitioners would just tell me that I should be patient with him he would outgrow the crying, but could not explain the breathing. At six months I was told that the boy is just growing slowly and might be having problems with his bones. That is when I was referred to a hospital in the city where he was diagnosed. The boy is twenty years old now but just lies down.

Mma Prince: *Prince is ten years old; he was diagnosed with cerebral palsy at eighteen months. Prince cried a lot as a baby. Although I was a new and young mother, I felt that my child was not developing well. This is because he was not mastering milestones accordingly, the doctor told me that I should let my child develop as he does, there was no problem with the boy, and he would grow. One day Prince's eyes seemed to be 'crossed' I went to the pediatricians, who somehow that day decided to do a CT scan. It seemed the doctor was discouraged and disappointed at the results. He felt sorry that he could not realize that there was a problem early. However, he recommended therapy and referred us to the occupational therapist and physiotherapist.*

Well, the doctor showed remorse and continued to monitor the child's development.

Mma T.

I only learnt that my son, Tiro, was autistic when he was four years old. This was after several years of struggling with medical practitioners in Botswana. After being referred from one doctor to another, Tiro was only diagnosed in Johannesburg where it was confirmed that the boy was autistic.

Mma 2

I started noticing that Shima was different when I called his name and he wouldn't look at me at all. I went from one doctor to another, but there was no help, one of them even said it could be just a character if not spiritual matters. However, after a discussion with a colleague who suggested that it could be autism, and recommended that I take the child to ... from then the child was diagnosed with autism after a year. Hospital medical practitioners did not have much to offer except discouraging statements that seemed to be aimed at making me give up on my child

Disheartening revelations by medicals

Some participants felt that the health practitioners were insensitive when giving them details of their diagnosis. This is what Mma Motho said:

The doctor asked me if the baby cried at birth, and when I responded that the child did not cry the doctor just said; ...Mental Retardation! (sounding like a judge passing judgement at a court of law). There is not much to be done to help this boy, he will grow into just a cabbage; by this I mean he is not a normal baby and might not live longer than five years at most. The doctor was so hard I thought, he continued to tell us that ...in fact in other countries, if it is diagnosed early this child could have been aborted, there is just no help for him. I later learnt that my son's condition is cerebral palsy after seeking for help from other private medical practitioners. My son is now 18 years old and has never walked nor talked.

Mma Rosa: My eight years old daughter Rose has cerebral palsy. When she was born, the medical practitioners told me she was not going to live longer because she is abnormal. I was told that due to my thin frame, my daughter's core muscles and bones are damaged. I was told that the child will be nothing but a vegetable. The term of vegetative babies was familiar therefore I cried bitterly. The medical practitioner further told me that it was going to be a struggle to raise her because she was not going to grow like a normal child and there is no cure for her condition.

Discriminatory tendencies

Mothers' narratives revealed discriminatory tendencies by health care workers in some instances. This is what some of them said:

Mma Prince

Prince had a descendent testicle at one point which was only discovered at seven years. He was referred to a surgeon and this is what the surgeon said; He is not going to marry, he is not going to give you grandchildren...why make him go through this unnecessary pain... is he your only child? If so where is your husband, why don't you talk to him so that you make another baby who can give you

grandchildren?... I will not operate this boy and put his life at risk, yes.

I hear your fear of possibilities of him developing testes cancer, but we can monitor it every year than risk his life. Probability is high that he will not have cancer and might not live longer for the testicle to reach a cancerous stage.....

MmaBino

I used to put this boy in a wheel burrow to transport him to the hospital for therapy, but nowadays he is too heavy for me because he is growing. I try to tell the nurses but they tell me that they are only nurses but not transport officers... this is what one of them said; mma you need to try your best to bring him for therapy, the hospital does not have enough transport to cater for all patients so you too should try....

Resilience

Mothers revealed that they use different strategies to cope with their situations of caring for children with developmental disabilities. Some of them revealed spirituality as a cornerstone of their strengths while others revealed that hearing and reading other people's stories gave them courage. The mothers also revealed that internet is a very good tool they use for information. This is what some of the mother's said:

Mother 1

I constantly observe him, and seek information online and anywhere else just to understand my child. This has helped a lot. My son is strong, he used to have breathing and constipation, I try my best to manage this through diet and it is like each day I discover new ways on how I can help my child. Although he lives with this disability I thank God that through my mother's help, his brother and my constant search for information, my son has lived and is still going strong contrary to what the doctor had told us. Mogomotsi's strength has replaced sadness and sorrow in me/us with courage. I try my best once in a while to reach out with motivation whenever I hear or learn that someone has a child with cerebral palsy. I know hospitals can somehow kill one's emotions.

While some health workers have shown unkind and discriminatory attitudes, there are those who go an extra mile to support partly because of their

knowledge of the condition or passion for children. One mother revealed that while one surgeon at a local hospital viewed the child as fragile and asexual, other health care professionals at a hospital outside the country found it necessary for the child's undescended testicle to be corrected. She further confirmed that the boy's operation was successful and other surgeries will be done to help improve his gait.

Seeing a gem in my child kept me going

Research Question 2: How do the mothers of these children mould the gem they see in their children despite their experiences and challenges?

The mothers' stories revealed that despite the challenges and discouraging statements they receive about the conditions of their children with cerebral palsy and autism the mothers do not give up but rather continuously find ways on how to assist their children grow. This is what the mothers said:

Mother 2 Autism

Gladys said she started seeing different people and did her own research on ways in which she could control autism.

"I realised that it is a normal condition, and children with autism and neuro-developmental disorders need special care facilities that can help them develop at their own pace," she said.

Another mother said

Since I took my child to a private centre for rehabilitation here in Gaborone, my child has improved, she has now mastered toilet training and enjoys swimming.

.....proper facilities will help many parents with children with the same needs as it is not every day care centre that can help provide for these children.

Another mother said: contrary to the 'cabbage picture' I was given at the hospital few years ago, my child's condition has improved a lot as he now responds more to questions and can play with other children. There are still some challenges though.

The same was echoed by the mother of another eight years old girl as she shared how they, as a family,

continue to see improvement and great developments in their daughter's life.

Our commitment to finding out as much as we can about Chendzi's condition has helped us see her progress into a beautiful girl who is now improved a lot in social skills. From a vegetable we were told our daughter was going to be, we have a lovely girl, who enjoys singing, colouring and trying house activities. Chendzi enjoys some computer games... and we look at her and appreciate God.

Indeed it is a lot of work to raise a child with autism, but it is a lot of work to raise any other child if one is to appreciate the differences our children are born with. To us, Chendzi is such a joy to have, we chose not to be disgruntled by the medical practitioners' stories but to continuously educate ourselves. We are now able to share and encourage other parents who find themselves having to raise a child of whatsoever condition.

Learning from others

One day a colleague told me about sports as therapeutic to children with cerebral palsy. I shared with other mothers and we invited the colleague to give us a presentation. His presentation was lively during one of our tea meetings, we saw children like ours in other countries such as Brazil and United States of America swimming and playing other sports activities. We did not waste time but agreed with the centre where our children go for stimulation to engage a swimming teacher. Since then children swim, Prince loves water and is now able to swim. He has now been nicknamed the big fish both at home and school referring to the skill he portrays in the water.

After swimming Prince enjoys a peaceful sleep which is sometimes difficult for him. Prince wakes up a more calm and rested boy after the sleep.

I always look forward to his swimming session...

From 'abnormal and not worth spending on' to a football star.

My son is going to be a great footballer. Autism does not always follow him wherever he is, it's not even a death sentence like the picture the medics gave. After sharing with other parents from our group, reading online stories with the help of occupational therapist routine activities have been drawn and this has made Nyaladzo stable. When it's his time to play football, you just cannot put him off it. I have made a mini field with goal posts for him in the yard, he enjoys kicking the ball and making sure he has scored. Whenever he scores it is victory we all have to celebrate.

To every mother the life brought to earth is such a precious stone that needs to be dusted, refined and continuously shined to achieve its uttermost beauty.

Discussion

The findings of this study have revealed that mothers of children with disabilities face challenges that partly emanate from the marginalized position of persons living with disabilities in general. The revelations confirm Groce's, (2013) and World Health Organization, (2007) studies which were not specifically based on Botswana but yielded similar results. In addition, late diagnoses and lack of understanding of developmental disabilities have also been observed as a problem in other studies done in and outside Africa (Krahn, Hammond & Turner, 2005). Studies that focused on Cerebral Palsy in Africa also revealed that there is inadequate knowledge of the disability and lack of appropriate resources that could improve the lives of the children and their caregivers.

This study also found that mothers are sometimes met by harsh words and insensitivity from health care workers that most likely emanates from negative attitudes towards disabilities. For example, the statement by the surgeon that a child with Developmental disability does not need corrective surgery for undescended testes clearly indicates discrimination and devaluing of persons with disabilities. Moreover, these findings revealed the often held assumptions that persons with disabilities are asexual and fragile, hence in most cases they are even left out in most of the health campaigns. Furthermore mothers of children with developmental disabilities are challenged by their marginalized position of women in the society and the fact that they

have children with disabilities. This puts them in a precarious position where they are not able to assist their children adequately because of lack of support and discouragements by health workers.

Although mothers and their children face challenges, the study also revealed that these mothers actively try their best to help their children with disabilities. Through learning from each other and using internet and searching for information, mothers to a certain extent, play a critical role in helping improve the lives of their children.

Therefore, persons with disabilities especially intellectual disability are deemed fragile and asexual. Krahn, Hammond and Turner, (2005), documented health disparities between general population and people with disabilities. People with ID have been considered useless, unworthy of finding solutions for, because sometimes they are believed to be never going to heal but going to die quickly. The analysis also reveals that often times, people with disability are considered to be too fragile. This particular group is also side-lined or is hardly considered in health campaigns that include cancer screening and other health campaigns. In another study, Groce, (2013) argued that people with disabilities are rarely mentioned in HIV/AIDS campaigns and other related issues, and this is because they are considered to be asexual. This poses a health risk for this already marginalized people because studies show that they are not immune to HIV/AIDS, cancer and other diseases. This is because despite their condition of disability, they are normal and function like their non-disabled peers. The environment therefore creates problems for them and structures in place which are created by the so called normal.

However, in this case, the perseverance of the mothers to achieve the shine they desired from the forgotten gems, show resilience and agency. Despite that sometimes mothers of children with developmental disabilities encounter inadequate assistance and negativity by health care workers, mothers of children with disabilities in this study showed resilience. They stood up for their children by finding more information, in whatever possible way they could to educate themselves. The mothers' resilience is revealed as a strength that leads to improved health outcomes and longer lifetimes of their children.

Conclusion and recommendations

Generally the mothers' stories have revealed late diagnoses and inadequate knowledge of Developmental disabilities by the health workers. In addition, discriminatory tendencies were also revealed which also show ignorance and/or cultural and negative assumptions about disabilities by health workers. In order to improve the services for children with intellectual disabilities, mothers' experiences should be heard and taken into consideration as the mouthpiece for their children who in most cases cannot communicate their experiences. Therefore, it is imperative that studies be conducted on the experiences of the information and solution seeking mothers of children with developmental disabilities with reference to health care. There is also need for public education on developmental disabilities. The study also revealed that where health care workers are supportive and understand developmental disabilities, mothers were able to access the limited resources that they were advised to use and they found that revealing.

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