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Parenting children with Down syndrome: Societal influences

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Abstract

Most studies of parenting children with Down syndrome (DS) have been conducted in industrialized countries. They suggest that sensitive communication on the part of professionals, and social support, can lead to acceptance and positive adjustments in the family. This study examined the impact of a diagnosis of DS on Ecuadorian families, in particular at how the diagnosis had been communicated and received, as well as the feelings and experiences which followed. Despite considerable progress in recent years, Ecuador is still marked by discriminatory attitudes which affect children with disabilities and their families, and by the persistence of widespread poverty. This qualitative study, conducted in Cuenca, Ecuador's third largest city, is based on a focus group discussion and four in-depth interviews with Ecuadorian parents of DS children attending a specialist center in the city. The study shows that, reflecting the effects of status differences and lack of appropriate training, professionals rarely communicate a DS diagnosis in an appropriate manner. Further, it is shown that lack of social support, and the widespread stigmatization confronting children with DS and their families, hinder development of positive and empowering adjustments that would best serve the child's and the family's interest.

Keywords

Communication skills, Down syndrome, Ecuador, family, stigma

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Introduction

On being told their newborn baby has an impairment, parents tend to react with a mixture of shock and disbelief, followed by denial (Zappella, 2016). As the reality becomes undeniable, feelings of guilt, fear of the reactions of others, and uncertainty regarding the future emerge (Fortier and Wanlass, 1984; Mulcahy and Savage, 2016). Torn between powerful and conflicting emotions, parents live through a stressful period in which coping depends on support from one another, from extended families, friends, support groups, and skilled professionals (Yildirim, et al., 2012). Some studies have found more positive sentiments slowly emerging. Parents may come to see caring for a child with a chronic disability as giving meaning and purpose to their lives: a source of self-actualization and fulfillment (Schwartz, 2003).

The needs of children with different impairments differ, as do the practical and emotional challenges which families face in providing for them (Landsman, 2005). Down syndrome (DS), the most common genetic cause of intellectual disability, is generally associated with a distinctive phenotype, and may involve delayed growth, additional health problems, and difficulties in carrying out activities of daily living, as well as intellectual deficits (Chapman and Hesketh, 2000). Some studies have suggested that parents of children with DS enjoy greater well-being than those of children with other intellectual disabilities. However, it has also been suggested that this so-called 'Down syndrome advantage' is an artifact of income differentials which vanishes when family income is controlled (Stoneman, 2007). What seems clear is that a family's initial response to the birth of a child with DS, as indeed of any disability, is influenced by the way in which it is given the diagnosis (Baird, et al., 2000; Van Riper and Choi, 2011). All too often, this is done insensitively. Parents resent the lack of compassion shown by many medical professionals, or the lack of information provided, or the emphasis solely on future hardships (Goff, et al., 2013). In a large-scale postal survey of members of the US parents' associations, the majority of mothers who had received a postnatal diagnosis of DS reported being frightened and/or anxious after learning the diagnosis. This was all the more so when physicians were perceived to be emphasizing only the negative aspects of DS (Skotko, 2005). Mothers in this study complained that few health care professionals gave them the up-to-date information they wanted, or had anything to say about the positive aspects of DS (Skotko, 2005).

Improved communication between parents, family, community, and the health system can increase the satisfaction and the well-being both of the children with DS and their parents (Marshall et al., 2014). As parents begin to value the child as a source of enrichment in family life, positive adaptations can develop (King et al., 2006; Skotko et al., 2011). In a mixed methods study of American parents of children with DS, grouped by age, Goff et al. found that certain indicators of parents' levels of stress (or difficulty in coping) fitted a U-curve. Stress was greatest when children were under five years of age, declined, but then rose again post-adolescence (Goff et al., 2016). Positive sentiments and adjustments were more likely the less uncertain parents felt, and the more hopeful regarding their child's future (Truitt et al., 2012). An in-depth qualitative study of New York mothers of children with DS found that most did not see their families' experiences as having been characterized principally by suffering and hardship (Lalvani, 2008). This study found that many mothers had shifted their focus of attention from their own child's diagnosis to matters of social inclusion and rejection. The author interprets this as suggesting that 'mothers of children with Down syndrome locate disability not only in their child but also in the social and political environment' (Lalvani, 2008, 442).

However, it remains unclear which aspects of the social and political environment affect a family's experiences of caring for a child with an intellectual disability. Most published studies, conducted in rich industrialized countries, pay little attention to the characteristics of the society. Despite this dearth of evidence, it is likely that not only access to services but also social norms and values influence what adapting to parenting a child with an intellectual disability entails (O'Shea et al., 2012). A society in which habits and customs reproduce inequalities, in which stigmatizing attitudes are common, exacerbates the difficulties for many families (Lam and Mackenzie, 2002). Thus, in a poor district of Lima (Peru), a child with an intellectual disability coming from a respected family was more likely to be accepted in school and in the community than one from a less respected family. The authors note that their conclusions agree with those of a study in Mexico, where 'a combination of insufficient family resources due to economic deprivation and social deprivation' also exacerbated the social exclusion of people with intellectual disabilities (O'Shea et al., 2012, 257-258). The same norms, the same inequalities, will generally characterize health care providers' behavior toward their patients. Thus, a study conducted in Medellin (Colombia) found that health workers tended to communicate the news of the birth of a child with DS insensitively and without empathy, making parents uncertain and fearful regarding their child's future (Bastidas and Alcaraz, 2011). There is little or nothing to give parents hope for the future or help them develop the positive sentiments likely to be in the child's and the family's best interest.

Latin American societies such as these are marked not only by their high degree of social and economic inequality, but also by the important role that religion plays in people's lives. For many caregivers, in particular, their faith is an important source of emotional support (Caqueo-Urizar et al., 2016). A Brazilian study found that many mothers used religious rituals as a way of coping with the fear evoked by having been told of their child's DS (Nobrega and Oliveira, 2005).

Ecuador too is an overwhelmingly Catholic society, in which their faith and religious observance are central to most people's lives (Muñoz, 2016; Lyons, 2001). Despite the fact that the 2008 Constitution specifically acknowledges the rights of the country's indigenous communities as well as of people with disabilities (notably Articles 47 to 49: see Asamblea Constituyente, 2008), the country is still marked by great social and economic inequalities. Many, especially from the indigenous communities, live in poverty and lack access to formal health care. There has been substantial emigration, with children left in the care of one parent or a grandparent, and parents obliged to develop new forms of co-parenting at a distance (Pribilsky, 2004; Rae-Espinoza, 2016).

Previous work showed that the caregivers' accounts of their experiences raising a deaf or hearing-impaired child refer to distinctive features of Ecuadorian society, including the importance of religion, lack of access to or trust in the health care system, and family functioning, which reflects the country's extreme social stratification (Huiracocha et al., 2015). That study identified two distinct clusters of experiences. On the one hand, there were parents who had access to both the economic and the social resources needed to cope. They could rely on their extended families and on peer support. On the other, there was a group almost completely lacking in social as well as economic resources. These were parents whose extended family, itself possibly vulnerable and disadvantaged, shunned rather than supported them.

In the study reported here, we look further into influences from Ecuador's distinctive social environment. This article focuses specifically on (i) how families received a diagnosis of DS and (ii) how the families subsequently adapted and coped.

The present study

Cuenca, situated at 2500 m in the Andes, is Ecuador's third largest city. The city has been a pioneer in establishing a system of municipal preschools (*Centros de Desarrollo Infantil*), though few of these accept children with disabilities, or make appropriate adaptations to the program for those who are admitted (Huiracocha et al., 2012).

Between January and April 2010, we carried out a qualitative study in a specialist center for children with DS located in Cuenca. The study aimed to examine the impact of a DS diagnosis on families, in particular at how the diagnosis had been communicated and received, as well as the feelings and experiences which followed. Although at that time Ecuadorian law did not require a review by a research ethics committee, the proposed project was reviewed by the university's research office, in the light of the Helsinki Declaration. The purpose of the investigation was explained in person to all parents whose children attended the center and volunteers were invited to participate in a focus group. Parents were told that discussions would be recorded, and that they would be free to withdraw at any time they chose. Of the 19 parents (9 couples and 1 single mother), 8 agreed to participate in the focus group. Nonparticipants gave a variety of reasons for not wishing to participate, including discomfort at the recording of discussion. Topics for discussion in the focus group were elaborated in relation to four axes: location of the child's birth, the feelings of the parents on receiving the DS diagnosis, family circumstances and relationships at the time of the birth, and relationships with health care professionals at the time of the birth. Parents participating were aged between 28 years and 40 years, their children with DS were aged between less than two years and six years, with the exception of one 16-year-old adolescent¹. All except one participant were married and lived with their partner. The socioeconomic and educational level of these parents was well above average for the city. We knew from previous work that some parents would find it difficult to talk about their real feelings. In a Catholic society such as this, any child is to be seen as a blessing for which one must thank God. To express sadness or fear for the future is then an implicit denial of one's faith. To enable parents who wouldn't want to admit to such sentiments to communicate their feelings less directly, we provided paper and pencils. We invited participants to make drawings which could then be discussed (Eldén, 2013). Thereafter, four interviews were conducted with parents selected on the basis of the distinctly positive attitudes expressed in the focus group (two interviews) and distinctly negative attitudes (two interviews). Three of these interviews were with the mother alone and one with both parents. All interviewees agreed to proceedings being recorded and interviews lasted for an average of two hours. Data reduction, coding, and analysis were done manually using open descriptive coding. All investigators participated in the analysis and interpretation of data: the analysis being subsequently reviewed by a psychologist. In this analysis, we draw on both the focus group discussions and the interviews.

Results

Communicating and receiving the diagnosis

None of these mothers was happy with the antenatal care she had received. Mothers had been frightened of giving birth, and health care personnel, unprepared psychologically, tended to delay showing the baby to its mother when it was found to have DS. The diagnosis was generally not given by a gynecologist or a pediatrician, but left to nurses or whichever resident happened to be on duty. These arrangements only added to the anxiety, and women were often left with strong

feelings of denial. One of the mothers was actually sedated as medical staff tried verbally to force her to accept her son. Another had been shocked by a priest, brought to offer consolation, but whose words gave anything but that. As she later recalled what he had said

Look, I'll tell you something, you don't need to feel guilty, it's your age, that's all . . . God has sent you an angel, and you'll see that will give you all manner of blessings, and I'll tell you something else: if you accept the baby you will live and if you right now say no, God will leave you and you'll be left with no son and with only regrets

Responses of the parents in this study point to the whole gamut of inappropriate communication on the part of the medical professionals:

OK, what he did was . . . he told me in such a terrible way . . . [pause] . . . he finished me, he killed me, really, with the ugly words he used to tell me.

Professionals had been arrogant:

He said it like this . . . the girl is a Down . . . I said – but how can you say that if you . . . no, I have a clinical eye . . . just like that . . . such a dictatorial manner, so heartless;

and had seemingly lacked knowledge of the particular case:

I don't know if he'd even seen the child. Or maybe just lied to me. Anyway he told me it's a lovely male, it's healthy;

They had also threatened:

If you don't accept your child, well, then give him away!

And had held back or delayed providing information:

As soon as they took him out of my belly, they said take a quick look and they took him away . . . afterwards . . . the nurses had changed, they said: wait until the other ones come

It appears from these mothers' accounts that many doctors had been unable to deal with a situation which they themselves found stressful. The result was a retreat into silence on their part:

I don't know why the doctors keep at such a distance . . . they don't say much . . . they always look busy . . . they never explain what's happened. It's even worse in the social security or in hospitals where the doctors keep changing. You never know whom to ask . . . No one says anything. They keep silent . . . like they're looking at their shoes. You remember moments like those.

Occasions on which supportive communication had helped parents to imagine a positive future were rare. More commonly the way in which mothers were informed evoked feelings of pain, fear, and sadness. The mothers' feelings inhibit their trying to analyze the situation and weigh up possible alternatives. Disturbed, they become disoriented and confused by a situation so different from what they had hoped for:

I said 'My son? No no no that's not my son. You're wrong', I said because the doctor who showed me . . . no no . . . that can't be my son . . . [pause] . . . I said you are wrong. I don't see that a baby like that is born here

Family adaptations

The birth of a child with an impairment not only brings additional work for a family, but may also challenge family members' existing responsibilities and interrelationships.

She changed all of our lives, because my children . . . the process of acceptance was a chaos . . . adjusting to our new responsibilities, new roles . . . it affected all of us. But I can see that things are better now. They all work with me, help me . . .

Here, it was the women who were burdened with almost all additional caregiving responsibilities:

I took for granted that my husband worked, he has a job . . . all the others are busy . . . in effect it was me who more or less took on all of the care . . . because he is my son . . .

Questions regarding the roles of different family members rarely elicited any response. There was little awareness of the functions and roles of individual family members, so that narratives tended simply to reproduce what we believe to be institutionalized, and typically gendered, social patterns (although no studies of the distribution of roles and tasks in Ecuadorian families have been published). The mother is seen as the spiritual hub of the family, responsible for the care of the children, for household tasks, and for protecting the family unit against disruption. The children are there to study and, but only when they have time, to help their mother. The father is there to work, to provide economic support, but to keep distance from women's concerns. In the interviews and in the focus group, mothers scarcely referred to support from their husbands. If anything, it is other people, closer, who provide emotional support. What is striking is a silence, a distancing, and an apparent pulling back, on the part of most fathers. They seem to be reproducing stereotypical male behavior patterns as given by clearly distinct gender roles. They express no feelings and they cry no tears. Seemingly distant from the care of their sons and daughters, they appear to live outside the household.

Members of the mother's family (though rarely of the father's) were willing enough to give advice, but unwilling to get much involved in the search for ways of coping. As one mother put it

When they learned that I had a child with Down . . . my family still came to visit . . . my eldest brother came, my sister-in-law, my other brothers . . . they hugged me and said 'so how are you'.

Almost all the families had difficulties acquiring the extra income to pay for the therapies the child needed. Specialist institutions often demand payments from prospective parents which are beyond the family's means, thus cutting the families off from their services.

We'd have to pay a taxi to go and a taxi to come back, to buy medicines for my daughter, milk . . . sometimes it wasn't possible to arrange therapy at the social security and when we had a bit of money we'd pay for private therapy . . . but we couldn't always . . . sometimes there just wasn't the money for it

It was not only money that was in short supply. Just as importantly, there was a lack of time for relaxation or enjoyment. All these parents suffered huge mood swings, passing constantly from

sadness to happiness and back again, reflecting phases in their struggles to overcome the problems they faced. The result, in many cases, was a gradual decline both in self-confidence and social participation. As one mother explained:

I gave up going to the gym to which I had gone every morning. I stopped visiting my parents . . . I stopped going out . . . I began to live each day alone with my daughter and I began to focus just on doing all the practical things I could

Sandra, the 39-year-old mother of a 15-month-old daughter with both DS and cerebral palsy, described the drawing she'd made in the focus group:

First I've drawn a woman crying with her children in her arms . . . then I've drawn a woman with her children, with Sofia and my other two children, and with a fire on top of my head . . . you know. God will forgive me for putting it there. It looks like the sacred spirit but really, it's the strength that God gives me and that I draw on to be able to face life . . .

After the initial shock, the affective processes which follow involve these mothers interpreting what has happened not only cognitively but also spiritually. Religious beliefs have a complicated significance in this context. On the one hand, they render mothers vulnerable to the chastisements of priests, as described earlier. Yet for some mothers in this study, faith served as an important resource in making sense of their child's condition. As one mother put it 'they are now our little angels sent by God. They have a mission, they accompany us, they are sweet and affectionate'.

In the Ecuadorian context, it is difficult for parents to develop the positive appreciation of the contribution children with DS can make to family life. Too much stands in the way, not least the negative attitudes that predominate in this society.

Because they call them little imbeciles (*tonditos*) . . . because people keep staring at them . . . because they are made fun of . . . or because people are scared of them . . . Me too, when I saw them I was scared . . . because I'd never seen anything good in them . . . I'd never seen them as you see them on internet . . . young people with Down who speak well, work, go to school. Why does God send children like these? I've seen so many people who make fun of them . . . they mock and it drives me crazy . . . I was capable to going up to them and saying . . . OK why do you laugh? They're people just like us, they are children of God

The few positive sentiments expressed in the interviews were provided by people who had internalized new paradigms of diversity, of inclusion or—in the case of the mother of the 16-year-old adolescent—had come to understand the capacities of people with DS.

Discussion

It is well established that being given a DS diagnosis in a sensitive manner can give parents hope and can facilitate their acceptance of the situation. Such has not been the experience of parents in this study. Previous research has shown that the greater the status difference between doctor and patient, the poorer the quality of the communication (Peck and Conner, 2011). The high degree of social stratification in Ecuadorian society expresses itself in the arrogance and lack of empathy shown by many health professionals in communicating a DS diagnosis. Comparable with what Vehkakoski (2007) found in Finland, doctors were unable to deal with a situation which they

themselves found stressful. They had not been taught the skills needed for the sensitive communication of a diagnosis, or for providing care adjusted to the needs of the family, such as family-centered care (Pickering and Busse, 2010). What happens thereafter depends on the characteristics both of the individual family and of the society, though few studies have examined these societal influences. This analysis of the experiences of middle-class Ecuadorian parents finds little evidence for the emergence of the positive sentiments and adaptations identified in some studies in wealthy 'Northern' countries (Schwartz, 2003; Skotko, 2011). Despite growing labor market participation of women in Ecuador, as elsewhere in Latin America (García and de Oliveira, 2011; ILFAM, 2016; Observatorio de los Derechos de la Niñez y Adolescencia, 2010), little change in the division of roles in the family seems to have taken place. The birth of a child with DS reinforces the highly gendered divisions of responsibilities in the household, common in the country, adding to the stress of already overburdened wives and mothers. In some cases, the result is a disruption of conjugal relations, leaving a mother to cope alone. Religious faith plays a complex role. On the one hand, as Pillay et al. found in Australia, religion renders some mothers vulnerable to the chastisements of priests (Pillay et al., 2012). On the other hand, as was also found in Brazil, for some mothers their faith serves as an important resource in coping (Nobrega and Oliveira, 2005). Finally, and despite the country's inclusive policies, children with DS and their families still face stigmatization and exclusion. These characteristics of the society inhibit development of the qualities of resilience, the action-orientation, that enable some families to provide their son or daughter with DS with a decent quality of life.

Limitations of the study

The study was limited by the small and non-representative sample of parents participating. It was a small-scale study, carried out among a group of middle-class urban parents. In the light of previous research, and of Ecuador's extreme stratification, the problems identified are likely to be far greater among the rural poor. Further research should therefore focus on a larger and more geographically and socially diverse population.

Implications for practice

Diagnoses of this kind should preferably be given by a familiar and trusted medical professional. Most importantly, health professionals should be taught how to present a diagnosis in a sensitive manner, as well as the elements of family-centered care.

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Note

1. Before entering the centre in which the study took place the latter had been moved from one institution to another, and had spent the previous six years at home with no specialized attention whatsoever.

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