

Title: Qualitative understanding of parental observations of quality of life in Australian children with Down syndrome

Running head:

Quality of life in Down syndrome

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ABSTRACT

Objective: There are many challenges to health, functioning and participation for children with Down syndrome yet the quality of life (QOL) domains important for this group have never been clearly articulated. This study investigated parental observations to identify QOL domains in children with Down syndrome and determined whether domains differed between children and adolescents.

Method: The sample comprised 17 families whose child with Down syndrome was aged 6-18 years. Primary caregivers took part in semi-structured telephone interviews to explore aspects of their child's life that were satisfying or challenging. Qualitative thematic analysis was implemented using a grounded theory framework to identify domains. The coded dataset was divided into two groups (childhood and adolescence) at three age cut-points to observe whether differences existed between the coded domains and domain elements: (1) 6 to 11 years with 12 to 18 years; (2) 6 to 13 years with 14 to 18 years; and (3) 6 to 15 years with 16 to 18 years.

Results: Eleven domains were identified: physical health, behavior and emotion, personal value, communication, movement and physical activity, routines and predictability, independence and autonomy, social connectedness and relationships, variety of activities, nature and outdoors, and access to services. No differences in domains and domain elements were identified across childhood and adolescence.

Conclusion: Our data form a preliminary framework from which to design investigations of the child's perspectives on life quality and suggest a range of necessary supports and services.

Keywords:

Down syndrome; Quality of life; Qualitative research; Intellectual disability

INTRODUCTION

Down syndrome is a common known cause of intellectual disability, occurring in approximately 1 - 1.45 per 1000 live births^{1,2} Some children are able to speak, read and manage daily living activities, whereas others cannot speak or read, and need support to complete daily tasks. Associated problems commonly include congenital heart disease, hearing and vision problems, obesity, constipation and more rarely, leukaemia³ and autistic features.⁴ The phenotype is diverse.

Quality of life (QOL) refers to feelings of satisfaction in relation to life experiences including physical, material, social and emotional wellbeing.⁵ Domains identified as important for adults with mild intellectual disability include personal development, self-determination, interpersonal relations, social inclusion, rights, and factors related to their emotional, physical and material wellbeing.⁶ However investigations of QOL in children with intellectual disability are limited. A study of young people with disability (n=20), including eight with *mild* intellectual disability (three with Down syndrome) reported that family, friends and participation in activities were important, as were feelings of resilience and self-esteem,⁷ but this sample was small and did not include those unable to self-report. By definition, QOL is an attribute that we evaluate through self-reflection with self-report the gold standard. If cognitive ability precludes child self-report, parents act as proxies⁸ and their reports typically guide much decision-making. Parent observations of a more diverse sample of children with Down syndrome could usefully provide preliminary data on QOL and inform later systematic investigation of child perspectives.

We recently explored QOL domains for children with Rett syndrome, a disorder causing severe intellectual and physical disability in females.⁹ Parent-reported observations enabled

us to identify ten domains relating to health and wellbeing, daily activities, and community and services.¹⁰ Domains of QOL can vary by diagnostic group¹¹ and these domains for Rett syndrome may not apply to children with a generally milder intellectual disability such as Down syndrome. This current study explored parent observations of QOL important for a sample of children with Down syndrome including children who cannot speak for themselves. We also sought to ascertain whether different domains would be observed for children and adolescents.

METHODS

Participants

Established in 1997, our Western Australian population-based database initially included children with Down syndrome born from 1980 to 1991 who were identified through the Disability Services Commission of Western Australia. In 2004, the database was extended to include children with birth years up to 2004¹² and at the time of recruitment in 2014, families of 95 children aged six to 18 years were registered. Three of the families with younger children with Down syndrome had recently been recruited through Developmental Disability WA (a community organisation in the disability sector) and the Down Syndrome Association of Western Australia.

Seventeen of 18 mothers initially contacted agreed to participate in the study. Recruitment was purposive to optimise variability within the sample for sex, age, health issues and area of residence. The children (9 females) were aged 6-18 years (seven younger than 12 years). Thirteen (76%) families lived in an urban setting and 13/17 of the mothers had a post-school qualification such as trade certificate, diploma or degree. Six (35%) children had experienced

complex health problems such as leukaemia, epilepsy or atlanto-axial instability or associated disabilities including autism and deafness. Selected questions from the Index of Social Competence¹³ were used to identify levels of skill and independence in performing everyday tasks, and responses were dichotomised. Thirteen (76%) children had some intelligible speech, eight (47%) were independent at mealtimes and six (38%) for personal care. Parents of eight (47%) children reported behavior problems.

Procedure

Qualitative research was undertaken using a grounded theory approach.¹⁴ Interviews were conducted by three researchers (██████████) who were qualified psychologists with previous interview experience. Semi-structured stem and leaf telephone interviews took approximately 60 minutes and were digitally recorded. The questions were provided to the parent to consider prior to the interview. The interviewer probed with additional leaf questions to capture observable behaviors that illustrated aspects of life quality - *“How do you know?”*; *“What does that look like to an outside observer?”*; and *“Why do you think that is?”*.¹⁰

Recordings were transcribed and given to parents for member checking, which was completed by 69% (12/17). Thematic saturation was achieved after participation of 17 parents, determined by parallel coding of data during the interview period to confirm that new themes were not emerging. A Consumer Reference Group (CRG) meeting was held to review the domains and further inform our coding and interpretation. Ten parents (one father) whose children were aged 6 to 27 years attended including three parents who participated in the interviews. Ethical approval for this study was provided by the Human Research Ethics

Committee at the University of Western Australia, Western Australia (RA/4/1/6931) and parents provided informed consent to participate in this study.

Analyses

To fully understand the dataset, transcripts were read and reread by NM and data describing observable behaviors were then coded using NVivo (10th Ed, QSE International Pty Ltd, Burlington, MA). Domains of QOL as well as elements within those domains were ascertained using data describing observable behaviors. Three researchers (JD, AE, NM) reviewed and interpreted the domains and coding and joint discussion was used to establish a consensus. The coded dataset was separated into groups (childhood and adolescence) to observe whether the domains and domain elements were represented across both age groups. Coded data for children and adolescents were read and compared, using three different age cut-points to define the separation, because there are limited data available on adolescence in Down syndrome and no specific age cut-points are recommended. Representations of domains and domain elements were compared for children and adolescents aged: (1) 6 to 11 years with 12 to 18 years; (2) 6 to 13 years with 14 to 18 years; and (3) 6 to 15 years with 16 to 18 years.

RESULTS

Quality of life domains

From our analyses, 11 domains were identified as important components of QOL. Parents in the CRG concurred with the coding of the data. Sample quotes from each of the domains are provided in Tables 1, 2 and 3.

Health and wellbeing (Table 1) “*Physical health*” included elements of fatigue, pain, respiratory infections and comorbidities such as leukemia. Parents discussed the importance of their child getting adequate night-time sleep to ensure sufficient energy to sustain alertness during daytime activities.

“*Behavior and emotion*” included variations in body language and expression that indicated happiness, cheeky humor, helpfulness, or engagement with people and activities.

Alternatively, other observations indicated moodiness, anxiety, stubbornness or aggression.

For example, increased talkativeness often indicated happiness, whereas less socializing or an unwillingness to participate tended to indicate unhappiness.

“*Personal value*” referred to how the children demonstrated their feelings of self-worth. This domain included elements such as the child indicating satisfaction when expressing their point of view; the importance placed on having others respond to their viewpoints; and being recognized for their individual actions or roles. For example, parents described their children’s desire to have their own voice, to be taken seriously and to be treated as an equal by their peers.

Daily activities (Table 2) “*Communication*” comprised verbal or non-verbal expression of information to others. This domain included elements on ease or difficulty making choices, conveying feelings and sharing details of their own experiences. For example, many parents discussed their children’s ability to share their specific interests (eg, sports) as topics of conversation to engage the people around them, whilst others described their child’s frustration when unable to verbalise. Electronic devices were also discussed as a means of assisting some children with sharing their stories.

“Movement and physical activity” related to opportunities to be mobile and active. Many children had learnt a variety of skills to be able to pursue different forms of recreation such as dance, bowling, horseback riding or being active in water.

“Routines and predictability” referred to the aspects of the children’s activities and environment that were stable and familiar. This domain included elements such as feeling comfortable with following known patterns of activity and being around familiar people. For example, some parents described how their child felt confident in recognizable settings and thrived on routine. Changes in routines, particularly when sudden, could trigger more challenging behaviors such as opposition or aggression.

“Independence and autonomy” included learning new skills and knowledge, and accomplishing tasks that provided opportunities for the children to have control over their own actions and aspects of their environment. Elements related to choice and personal preferences, developmental maturity and meaningful activity. For example, parents described their children’s enjoyment in choosing their clothes, helping to prepare their preferred meal, or showing others a newly learnt task such as remembering a sequence of dance steps.

Community immersion and services (Table 3) *“Social connectedness and relationships”* referred to interactions within social settings. This domain included elements such as empathy and intuition, social inclusion and acceptance, and shared enjoyment and anticipation. For example, parents discussed their children’s expressions of love and affection when greeting people with hugs and handshakes; enjoyment of peer friendships; and the pleasure the children experienced when they helped comfort others in times of need.

Additional examples illustrated the children's sensitivity to how others respond to them and involve them in shared activities, and their excitement when sharing news or describing an activity or event.

"Variety of activities" involved participation in different home-based and community endeavours. This domain included activities such as music and play or hobbies. For example, the children might have enjoyed listening to their MP3 players and playing board games in the company of others.

"Nature and outdoors" referred to opportunities to be outdoors in the fresh air, interests in nature and time spent with pets. This also included going for a walk, venturing out to the local park, and enjoying outside activities such as gardening.

"Access to services" included elements such as service access, advocacy, and financial assistance, and how these factors impacted their children's life quality.

Domains for children and adolescents

Each of the 11 domains and domain elements were represented in both the child and adolescent cohorts when using each of the three age cut-points for the dataset. Sample quotes for younger and older children in Tables 1, 2 and 3 illustrate comparability across the domains and domain elements. The CRG also described consistency in their observations of each of the domains across their child's childhood and adolescent periods.

DISCUSSION

For children with Down syndrome, 11 QOL domains were identified that aligned well with definitions of QOL⁵ and the International Classification of Functioning, Disability and Health (ICF).¹⁵ The ICF is a model of conceptualizing the multiple aspects of life affected by disability and comprised four domains: Body Functions and Structures where deficits or abnormalities are defined as impairments; Activities and Participation where difficulties in performing activities are termed activity limitations and difficulties engaging in life events and situations are termed participation restrictions; Environmental Factors include aspects that are physical, social or attitudinal; and Personal Factors include aspects of the individual such as age.¹⁵ The domains “health and wellbeing” and “behavior and emotion” align well with impairments; “communication”, “movement and physical activity” and “routines and predictability” align with activity; and “variety of activities” and “nature and outdoors” align with participation. “Personal value” and “independence and autonomy” represent personal factors, and the domains “social connectedness and relationships” and “access to services” represent environmental factors.

Physical wellbeing included day to day issues such as poor sleep¹⁶ as well as serious health conditions such as the discomfort of leukemia or respiratory infections.¹⁷ Behavior and emotion was variable with some children observed as cheerful and content most of the time yet others experienced frequent challenging behaviours.^{18,19} A small proportion of our sample had also been diagnosed with an autism spectrum disorder,⁴ a comorbidity providing additional complexities for some children yet less often acknowledged during clinical practice.

Capacity to engage in meaningful activities was important. Parents described their child’s use of communication tools (eg, iPad) as valuable vehicles for sharing stories, particularly when

speech was poor. Most children enjoyed participating in physical activities whereas others were more reluctant to be active, instead preferring recreational use of electronic media.

Many children had a desire for routine and predictability, and to be given time to adjust and accommodate to expectations if these routines were to change. Consistent with our findings for Rett syndrome,²⁰ routines and schedules assisted with the child's stress management and engagement during daily life.

The quality of social relationships was critical to building a sense of personal value. Children with Down syndrome have been reported to have few friends, particularly those with poorer motor and communicative function.²¹ Our data suggested that aspects of day-to-day interactions including recognition of the child's efforts and opportunity to have their voice and opinions heard can support social functioning. Other community domains included participation in a variety of activities and consistent with our findings for Rett syndrome,¹⁰ the natural environment was associated with enjoyment and relief of stress. The child's capacity to accomplish more daily living tasks independently was ongoing²² and access to services for skill development over both childhood and adolescence was observed to enable greater capability and increased personal value.

Adolescence is usually associated with rapid biological change from approximately 10 years of age with subsequent development of new social roles.²³ This could reflect different QOL domains, as found when developing the Cerebral Palsy Quality of Life Questionnaire (CP QOL) measures.^{24,25} In the current study, we were unable to identify differences in the domains and domain elements between childhood and adolescence, despite assessing this with different age cut-points. We acknowledge that future research using child-report data could identify adolescent-specific domains not captured in the parent proxy-report.

The children of our recruited families represented variability in Down syndrome and enabled us to reach thematic saturation. Our response (94%) and member checking (69%) fractions indicated the importance of this topic to families. We included probing questions in our interview schedule such as “*How do you know this?*” to collect observable behaviors and therefore more closely represent what was enjoyable or challenging to the child, despite the informant being the parent. Many children with Down syndrome do not have verbal skills³ and reliable mechanisms to collect perspectives on QOL from children with intellectual disability have not yet been determined. These could include responses to visual images or choice-making scenarios and their clarification is important research for the future. Our foundation data will contribute to this future effort.

Investigation of QOL in children with intellectual disability who are vulnerable to health issues and suboptimal participation has been largely neglected. As such, we have conducted a qualitative study to identify the domains of QOL important to children with Down syndrome, some of whom were unable to speak, as observed by their parents. Our rich dataset provides a framework for the planning of comprehensive health, communication, social and participation supports. It also provides an evidence-based foundation from which to plan research that investigates the child’s perspectives on QOL that includes children that represent the breadth of issues observed in Down syndrome.

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Table 1: Sample quotes for the health and wellbeing domains

Domain	Element	Sample quotes
Physical health	Fatigue	<p>“When he comes home he's generally pretty tired. He just wants to come home and just chill out and then he'll be happy to do something.” 9 years</p> <p>“He got tired so you need the break half way through the day.” 13 years</p>
	Maintaining health and fitness	<p>“And the only issue that we've got is his weight, which I'm addressing at the moment with diet and exercise.” 10 years</p> <p>“He is actually quite trim and his contemporaries are not. And he is very proud of that, he is very proud that he has a pretty good body.” 14 years</p>
	Medical and hospital	<p>“At the moment it means she's had a month in [the hospital], she's had daily visits from the nurses, she has dressings for the wounds that are done. She can't do most things that most kids can do at the moment and that's because of this medical condition. And it may have a long term impact on her life, we're not sure how much so yet.” 6 years</p> <p>“And even just muscle strength and all of that, we're building back up. I mean she really struggled just to walk to school. So being healthy is helping us to sort of build where she is at now.” 11 years</p>
Behavioural and emotional wellbeing	Aggression	<p>“Tears, tantrum, kicking, slamming doors, swearing. It can be a little less dramatic but if it's a last minute cancellation, he goes off on full flight.” 10 years</p> <p>“He will refuse to do it, just say no, or he will just ignore you and pretend he hasn't heard, and it is usually a big sort of shouting match of ‘No, I am not going to’.” 18 years</p>
	Resistance	<p>“You know it is very hard if she does not want to do something. It is like trying to extract teeth. She will drag her feet, she is slow, but if she wants to go somewhere, wants to be somewhere, then she is dressed and ready to go, but the complete opposite when she is unhappy.” 9 years</p> <p>“She gets very, very stubborn – she just won't do it, as in she'll just blankly refuse. She might say she's not going to do it but then she'll just stand there, despite lots and lots and lots of words. She'll just stand there and refuse.” 13 years</p>
	Humour	<p>“...he'll do silly things. He's a big of a practical joker, he tries to pull tricks on us and that.” 10 years</p> <p>“She is enthusiastic; she laughs and jokes quite a lot. She actually has a fairly wicked sense of humour.” 18 years</p>
	Helpfulness and engagement	<p>“He's eager to participate in what you might suggest. Like whether that be going to school or going out for dinner or something like that. He's always eager to join in those sorts of things.” 9 years</p> <p>“... if I'm rushed and he can actually hang a basket of washing out on the line. You know, I'll say ‘Mummy needs to rush, can you do this?’ and he's very accepting to help.” 13 years</p>
	Body language and expression	<p>“That whole thing of body language, you know you can tell. Like yesterday she had a bad afternoon. When she came home she was quite introverted, she went and sat on the trampoline, very sullen and sulky, and with Down's kids their body language is quite expressive. If they are moody, their whole face relaxes so they can look quite unhappy.” 9 years</p> <p>“Although he has no speech he ... makes lots of sounds - happy sounds - and he puts his hands up behind his head and he wiggles his fingers when he's excited.” 18 years</p>
	Stress and coping responses	<p>“She just gets quite withdrawn or she'll look at me and she'll shake her head.” 10 years</p> <p>“Listening to her music. She has worked on, and we have given her strategies about having a safe place, in her imagination that she goes to. And she has created a safe place that in her imagination that is a beach, with nice warm white sand, and the feeling, and sound of the ocean and all that</p>

		sort kind of stuff." <i>18 years</i>
Personal value		"Yeah, so being valued for who she is and being accepted for what she can do and that's great for her." <i>10 years</i> "Just being accepted for who he is, not being judged and being able to have a voice himself, being able to say something and be heard and being taken seriously." <i>18 years</i>

Table 2: Sample quotes for the activity domains

Domain	Element	Sample quotes
Communication		<p>“Communication is her biggest challenge at the moment. Following instructions and speaking is really difficult. She’s not always understood by others. And still following instructions, I have to work hard on slowing down and reminding her to listen. And so we’re still working on that.” 10 years</p> <p>“And to see him try and interact with other children and say “Hello”, because they do not understand his tone of voice, or the words he is saying, or the words he is saying may not be what they are expecting him to say, they don’t respond at all. Or they respond in a way that he is not expecting them to respond, and that can be frustrating.” 15 years</p>
Movement and physical activity		<p>“[She] likes moving quite a lot. She’s very active so she loves dancing so she just loves dancing around to music. I think she finds it quite soothing as well and comforting. So she can listen to all different types of music and it can really affect her mood, so you can put as fast as The Wiggles and she is jumping around or you put Swan Lake ballet on and she’s very calm.” 6 years</p> <p>“We have a pool and he goes out and loves to get into the pool. He loves to swim for hours and hours literally in the pool either with others or on his own if others can’t go with him.” 15 years</p>
Routines and predictability		<p>“Yeah she likes just having predictability and she gets really upset if things change. So yeah she just likes having some stability and routine because she knows what’s going to be happening.” 6 years</p> <p>“At school he can predict it is going to happen but with something that is unusual or not a routine thing it is much harder to predict it. So we find he is happiest if we give him warning that it is going to happen. Then he can prepare himself with whatever he needs to do to be ready. But if we just say, ‘Come on we are off to the shops, get in the car,’ he finds that very unsettling and generally he is resistant to comply with that.” 15 years</p>
Independence and autonomy	Choice and personal preference	<p>“She finds that too difficult, so she just shakes her head and looks down. If it’s something that’s too hard she does the same thing, but she does that too if she doesn’t want to do her homework. She does that when she has to eat vegetables, she doesn’t like eating vegetables very much.” 10 years</p> <p>“She told me she wanted to walk home, so therefore she was walking home. And she felt good about it, she was independent.” 13 years</p>
	Developmental maturity	<p>“I think that sense of ‘I know what comes next so therefore no one has to tell me what to do’. I think he likes that sense of independence and even in the mornings, he certainly wants mum to stand back and not get involved or even remind him what to do. He knows what he has to do when he gets to school and he doesn’t want mum to prompt him.” 9 years</p> <p>“To be able to dress as independently as he can. At this stage he can’t do up his own buttons and he can’t do shoelaces, but to dress all his other dress he can do. He still has trouble with like, jean zips and the top button there. So he still does need assistance in doing up buttons and zips, but we’ve been trying very much to make him as independent as he can.” 13 years</p>
	Mastery and achievement	<p>“She remembered all the steps and she didn’t get stage fright. She did everything she was meant to do and she was very happy at the end of that show.” 10 years</p> <p>“She now is able to select, she’s learning and is really proud of being able to choose strawberries. How do you pick up a box and decide if that’s good or not? And she’ll say ‘Oh that’s mushy. Nope, put that back’. You know, how to select good capsicum, how to smell the rockmelon.” 16 years</p>
	Meaningful	<p>“She wants to help with putting things away afterwards, caring for the horses, going and getting and helping them with the saddles on and all of</p>

	activity	that now.” <i>10 years</i> “He loves work experience at a garden centre. After he had been there for a year or so, he was able to teach the new kids that came to do work experience.” <i>18 years</i>
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Table 3: Sample quotes for the community immersion domains

Domain	Element	Sample quotes
Social connectedness and relationships	Empathy and intuition	<p>“And one of her friends couldn't really cope with the noise and was sitting down holding her hands above her ears, one of her best friends. And she went up and sat with her for a while, put her hand around her, you know, put her arm around her and tried to get her friend to come up and dance with her. Her friend wouldn't do it but she was trying to involve her.” <i>10 years</i></p> <p>“He has one girl, at his school, who is not mobile and she actually spends a lot of time lying down. She is quite immobile. He will just lie down next to her and she does not speak, but he will just lie there and just be with her. And I consider her a friend even though they cannot speak to each other, but he will be with her.” <i>15 years</i></p>
	Family members	<p>“She shares interests, she sort of knows, she'll sit down and watch soccer with her dad and rugby with her dad and do things that he likes to do.” <i>10 years</i></p> <p>“She has a younger sister. They are actually very close in age only 17 months apart and [she] has become the older sister to [her] and [she] looks at her as the older sister. Sometimes I have to remind [my daughter] that she is not the mother as well because she keeps on you know 'reprimanding' [her] for doing things. It is like 'No ... that is my role as mother and not your role as sister to do that.' By the same token they are very close, and [she] would do anything for [her]. And on occasions has stood up for her if she has been teased at school and things like that. <i>13 years</i></p>
	Love and affection	<p>“She's very emotionally intelligent, so she knows if people are happy or sad. She's just delightful. She's just a really lovely child, she's very loving.” <i>10 years</i></p> <p>“He is very affectionate to family and shows his affection a lot toward family.” <i>15 years</i></p>
	Shared enjoyment and anticipation	<p>“If she has had a nice playtime at lunchtime, she will tell me she did hand stands with a friend.” <i>9 years</i></p> <p>“He will tell me things. He told me that his friend rang him up. It is obvious that he loves school because he gets himself ready and out the door really quickly. He will be organised well in advance. He will talk about it. He will check with me that I am going to take him to bowling. Every week, he checks 'Are you going to take me to bowling this Saturday?'" <i>18 years</i></p>
	Social inclusion and acceptance	<p>“... we took him over for a play date with his friends, on Saturday ...so he had a play date with his friends. So he was pretty happy then. But if that had been cancelled he just would have been devastated.” <i>10 years</i></p> <p>“Even though he is 18, our next youngest son is 14 and we've got some kids across the road who are 16 and 14 as well that are always out the front playing basketball or soccer on the lawn, and often he is quite happy to sit out there and talk to them. He doesn't necessarily want to join in but he's a part of it.” <i>18 years</i></p>
Variety of activities		<p>“[He] usually drags a box of toys out there and pulls out whatever toys he's playing with at the time. Whether that be astronauts or toys like Buzz and Woody or something like that. They'll go outside and get playing with things or drag it back inside.” <i>9 years</i></p> <p>“She also likes her music and having a MP3 player and headphones is really critical to her, as was well as having an iPad and DVD players so [she] can watch DVD's in her own time.” <i>18 years</i></p>
Nature and outdoors		<p>“She has pets and she loves to tell people about her pets. We have rabbits that breed and she'll be very excited to tell them when she's got babies. And people know that and they'll ask her.” <i>10 years</i></p> <p>“He loves to help gardening outside.” <i>13 years</i></p>
Access to services		<p>“... One place has told me they won't take her because she has special needs, and that's something that was completely outside our realm of</p>

		<p>experience.” <i>10 years</i></p> <p>“The support that is there is marginal. And it’s like the sort of thing where every six months, there’s a new specialist in the government department that is supposed to be assisting with [my daughter’s] development. But every six months there’s a new person coming in and they’ll develop new goals and plans and that sort of stuff. And then nothing happens in the next six months until a new person comes in and the same thing happens again. So it’s a little frustrating then and we end up not dealing with them because it’s just a waste of time. So a more consistent and user-friendly response from the government agencies would be of some use.” <i>13 years</i></p>
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