

ORIGINAL ARTICLE

The daily lives and occupations of Tibetan families who have a child with disabilities

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Abstract

The aim of this paper is to explore and describe the experiences of Tibetan families living in remote villages that have a child with disabilities. Focusing on their specific situations and the influences on their daily occupations, the study provides a deeper understanding of the families' experiences, perceptions, and expressed needs. Two families participated in an ethnographic study. Both participant observation and conversational interviews were used to collect data. A comparative data analysis revealed the following themes: 1) Families' views on disability and care provision: "What we have, we are willing to give"; 2) Families' occupational pressures: "One person needs to be the caregiver all the time"; 3) Families' desires: "That the child can feed and go to the toilet independently". Implications of the findings for practice in remote areas and cross-cultural contexts are discussed. These findings may help to provide a good foundation for occupational therapy practice in this context.

Key words: *Activities of daily living (ADL), culture, ethnography, Himalayas, occupational therapy, remote area*

Introduction

Today's occupational therapists face cross-cultural situations in their own countries of practice, as well as in occupational therapy services in non-Western contexts (1–10). Attitudes, beliefs, values, and behaviours may be very different between the client and the therapist.

In order to establish cross-culturally sensitive practice in occupational therapy, a deeper understanding of specific situations around the world is needed. People of every ethnic group have their own beliefs regarding health, preventative health, and how to take action in case of illness and disability (11). Understanding influences on health beliefs and behaviours

of particular cultural groups leads to better quality treatment (11,12).

Pre-understanding and experience

The first author is a female researcher with European occupational therapy education who has studied Chinese and Tibetan at a university in Qinghai Province China for four years. Altogether she has lived and worked in Qighai for 11 years, practising as an occupational therapist in a number of settings with a non-profit organization (NPO), including opening a therapeutic treatment centre in Huang Nan prefecture. This has enabled her to gain a

deep understanding of local cultures and languages and to reflect on her own cultural background.

Background and literature review

This research focused on the Amdo Tibetan people living in the mountainous areas in the northern part of the Himalayan plateau (13–15). The Amdo Tibetan families live sedentarily in houses, in villages, or as nomads in tents (13). A village often consists of several family clans who are related to each other. Some sedentary Tibetans are farmers and the nomads are mainly herders. There are extensive descriptions of their life and work in the literature (13,14,16–20). Few changes had occurred in the villages over the last 90 years (13,16–19), as there were minimal influences from outside (21). Tibetan culture protected itself strongly and successfully from the outside until the beginning of the twenty-first century, despite being influenced for around 60 years by the Chinese communist political system (22). However, with increasing access to telecommunications and changing politics new influences are emerging even there. A big challenge in the context of imminent change is that of low literacy levels. It is thought that about 60–80% of the population are illiterate.

Definition of culture

Understanding “culture” has been essential for the researcher in her day-to-day work in the Himalayas in order to provide a culturally competent occupational therapy service and also in relation to this research. Culture can be looked at from a sociological and occupational therapy perspective: Jones et al. (23) state that “Culture is a complex phenomenon that defies easy definition. Common among concepts of culture, however, is the idea of shared meanings through which members of a culture interact and communicate with each other. Shared meanings involve ideas, concepts and knowledge, and standards and rules of behaviour as people go about their everyday lives.” Awaad (2) additionally points out that “culture is multidimensional, operating at different levels, regional, community, family and individual”.

Tibetan culture and health

Tibetan culture is strongly connected to the Buddhist religion (13,14,24). Most Tibetans consider themselves Tibetan and Buddhist; ethnicity and religion are interwoven and cannot be separated (14). Buddhism is practised in people’s daily lives and

characterizes decision-making (13,14,20,25,26), with the religious leader (lama) playing a key part (25,27). There is limited research to date reflecting on the Tibetan people’s occupational views and perceptions. Occupation in the village is connected to survival and giving contributions to the monastery (20). Cultural beliefs are equally important in relation to sickness or disability, where the family, as the central unit, takes care of the patient. People believe in the existence of the demon of “ill health” which invades the human body (25,27). If a person in the family is ill or has a disability, they ask a lama to tell their fortune so they can worship the gods and Buddhas, and the lama offers prayer to remove the illness (25,27).

Formal healthcare provision in the northern Himalayan region

Little is known in the research literature about health and the provision of healthcare in remote areas of the Himalayas. A health survey conducted in Qinghai Province, P.R. China, among the Tibetan nomadic population showed that there was limited access to healthcare and a high rate of child mortality (28). People in remote areas may call on a village health worker who has very limited, if any, formal training (28,29) and occupational therapy is not part of the official healthcare system.

Children with disabilities

In Amdo Tibetan households, several generations live together in mud houses with a courtyard. In Buddhist society there is strong family bonding (25), and the realization of obligation and respect towards parents dominates in the relationship between parent and child (30). A newborn child is considered to be a reincarnation of being, since this child has already lived several lives and carries with him (or her) a history, and is seen as an individual with a personality of his own, determined by his karma (30).

In every village there are some children with disabilities. Whilst working in the villages with the NPO,¹ the researcher observed that the life-world of many children with disabilities is mainly their home, including the courtyard. These children may have limited opportunities for engagement in the wider community and day-to-day life. In order to provide a culturally sensitive service to these families, a deeper understanding of the underlying patterns of behaviour and the meanings of their culture is needed. The purpose of this study was to enter into the life-world of Tibetan families who have a child with disabilities and to explore their perceived needs and the influences on their daily occupations in relation to

caring for that child. The study aimed to answer the following research question: How do Tibetan families who have a child with disabilities while living in remote villages experience their situation and their daily lives and occupations?

Material and methods

Design

An ethnographic approach was chosen because the design focused on understanding the world of a specific group, namely Amdo Tibetan families that have a child with disabilities (31–36). In order to decode and record Tibetan families' situations and make them accessible to an audience, the researcher, as an "outsider" to the cultural scene, sought to obtain an "insider" perspective (32). This emic perspective was applied in order to understand how Tibetan families envisioned and experienced their world (33). Reality was constructed through the researcher's interaction with different family members as informants (31–33). Data were collected in the natural setting of the families' homes. Participant observation and informal interviews were combined in order to condense information and to improve the credibility of the findings (31,36–38). This design allowed the researcher to spend extensive time with a limited set of two families, observing them in their natural settings, and thus gain an in-depth understanding of their situations and experiences. Data were collected during a fieldwork period of eight weeks.

Ethical issues

Since there were no specific regulations concerning ethical considerations in the People's Republic of China (PR China) and no ethical committee in Qinghai province, the researchers followed ethical standards in accordance with the Helsinki Declaration of 1975² (39). Special attention was given to finding appropriate ways of respecting the dignity of the families. In a Tibetan village relationships are viewed as more important than agreements. Local authority structures were respected and the highest possible authority was asked for permission to carry out the research. After an oral introduction in the Chinese language and giving the research proposal in English to a leading doctor³ at the prefectural district hospital, written permission was given. In order to ensure anonymity and dignity, the participants were introduced to the project in a cross-culturally sensitive way (40,41). Informants received verbal and written information in the Amdo Tibetan language, ensuring that

participation was voluntary and they were guaranteed that all personal information would remain anonymous (42). Written consent was given in one family in agreement with the parents by the grandfather⁴ and in the other family by the mother of the child.

Sample

Two Tibetan villages were chosen to comply with the following criteria: 1) for feasibility the site should be located within reasonable travelling distance and have road access; 2) in order to be representative the villages should be of medium size; 3) there should be established trust and some kind of relationship with the village from previous medical work in the area as prerequisites to enter the village (43). Although it would have been possible to focus on one village only, the researcher looked for two villages to make sure that the families did not know each other, could participate independently and would not be influenced by each other's understanding and perceptions. Personal contacts were used to enter the Tibetan village (31).

The families were selected through purposeful sampling according to the following criteria: 1) the family should be open and not afraid to let an outside influence come into their house;⁵ 2) the family should be willing to share their experiences; 3) at least one family member should have had a minimum of three years of formal education, in order to have a person who could understand the introduction of the research and explain it to the rest of the family; 4) the age of the child with disability should be between six and 16 years old, so that the situation was not new to the family and daily life activities could be observed; 5) the child could be male or female; 6) the child could have physical or mental impairments, or both, as the diagnostic category is not a primary factor to be considered in this study; 7) the child should not have received previous occupational therapy treatment, so that the family's thinking was not influenced beforehand. Two families, one family from each village, were chosen to be explored in depth.

Data gathering

Due to the cross-cultural character of the study and to increase accuracy in data collection and language translation, the first author formed a research team comprising an ethnic Tibetan woman who was a medical doctor, an ethnic Tibetan nurse, and an ethnic Han Chinese who functioned as a language translator. The common language among team members was Chinese. The whole team was introduced to the purpose and intent of the study and trained in data collection. Team members (including the author)

recorded field notes and observations independently during and after each visit. Immediately after data collection, the investigators compared notes and impressions and reconciled any differences through in-depth discourse on the data set (32,34). All procedures although guided by the author were carried out in consultation with the team members, to ensure cultural sensitivity. The research team's degree of participation could be described as that of a guest in the Tibetan homes. This meant that everybody sat down and was served tea at every visit. As the research team visited the families' homes frequently, a stronger relationship and openness from the family members towards the research team developed (31–36). In order to gain an emic perspective on the families' way of envisioning their world, and to have access to "as normal as possible" daily life, extended times of two to three hours per visit were spent in each family's home—a combination of observation and immersion (36). Participant observation was conducted at different days and times of day, in order to observe different daily life situations.

In the second half of the field study, the research team prepared general and open questions in advance, in order to focus data collection and to help organize and structure data (34). Some of the interviewing was semi-structured in order to ensure that a number of key points were discussed with each family (37). Questions developed around the family's customs, values, and beliefs, as well as their thoughts, attitudes, and feelings towards their child. As data collection proceeded, the enquiries became increasingly focused on emerging theoretical concerns (33). All conversations were written down in the field notes and the visits were carried out until a saturation of data appeared in the repetitive and redundant information of the participant's answers (33). Tape recording was not an option since the families would have been suspicious of the use of such a technical device. Several translation steps were made from spoken Tibetan to the transcriptions in English (37,40,41). The conversations were in spoken Tibetan;⁶ all three local team members wrote field notes in Chinese.⁷ The first author wrote her field notes in English. The handwritten notes were translated into English by the translator and then organized and stored on the computer by the first author.

Data analysis

The organization and analysis of the data collected went hand in hand and were an ongoing and integral part of data collection (32–34,36). Questioning occurred simultaneously with collecting and making sense of information. This was an ongoing process of

reformulation and refinement of the problem resulting in additional sub-questions that were transported into the field to uncover underlying meaning and cultural patterns (32–34,36). The main analysis took place after all data were collected and was done by the first author under the supervision of the second and third author. A grounded theory emphasis through a comparative method was applied (36). In comparing data, categories were identified, and relations between concepts and categories were drawn out in order to connect the family's reality with theory (36). During data collection it became obvious that the economic and daily life situation of the two families were different. This confirmed the researcher's strategy to analyse the families separately as a first step. A simple reading of the complete data set in English was performed to get an overall impression and overview of each data set. For a second reading, each family's data set was transferred as a primary document to the computer software Atlas.ti (36). Main units in the raw data were identified, focusing on possible meanings and patterns in the expressions of the family members, and by identifying units that seemed interesting to the researcher, in relation to the research question. In order to take the data apart and to look at the data anew with an analytic eye, an open coding was performed line by line; and arising codes were identified and named (36). The complete data set of each family was then screened again searching for experience and meaning segments in the text naming them with short memo titles. This process of going back and forth in each data set resulted in the identification of the themes pictured in several diagrams. After the analysis was performed for each family separately, the second analysis focused on the identification of a pattern between themes, representing a relationship between these themes.

To establish trustworthiness and limit biases, several steps were taken. Credibility was supported by the fact that there was a team of four people collecting and reconciling the data. Observations were conducted multiple times, at different moments during the day, and by different members of the families who were asked the same questions. The observational data and the interview conversation data were separately examined to justify themes and sub-themes. A peer debriefing was performed with an experienced anthropologist living in Qinghai and with the research team through the whole research process.

Findings

The findings are presented in three parts; first a description of each family's living situation, followed

by two diagrams picturing their experiences separately and before the themes and sub-themes are narrated. For the purpose of the study the child with disabilities was given a fictitious name and the family was named after the child.

The living situation of Tserang's (boy's name) family

Tserang's family's village was located close to a road, situated between a river and the foot of a mountain. About 130 families lived in mud houses which were built close to each other with small dirt trails in between. All the houses were marked with characteristic Buddhist symbols: such as prayer flags, prayer wheels, and altars. The people in this village were mostly farmers. There was a primary school, a Tibetan medical clinic, a small hospital, a temple, a little shop, and an electricity supply station. Tserang's family lived near the upper area of the village in one of the last houses. They had owned the house for two generations and at the time of the research the parents lived there with three boys. The parents were farmers who worked in the fields. Their first son, Tserang, was 12 years old and had severe physical and mental impairments. During the daytime he spent his time lying or sitting in the courtyard on the floor and every day he experienced several seizures. He was not able to stand or walk and for communication he was able to make some sounds but seemed to have limited hearing capabilities. Food was always given to him by one parent and his hands had only very basic functions. The two younger brothers were seven and three years old, and they went to school and kindergarten. Even by local standards the family was poor, as usually tools, animals, and food were stored in the courtyard; however, there was almost nothing in this family's house. The family's nutrition seemed sparse and mainly consisted of Tsampa,⁸ some milk, tea, and bread. The family had some relatives living in the village.

The living situation of Lhamo's (girl's name) family

Lhamo's family's village was surrounded by a village wall and was located across the bridge outside a small town. There were approximately 85 households and the houses were surrounded by high walls built next to each other using the neighbour's wall. The paths between the houses were concrete, which gave the village a clean impression. Buddhist symbols were visible with prayer flags on every roof, ornately carved wooden doorframes and images of idols at the doors. The adults had various jobs and during the daytime most of the people who stayed at home in the village were older people and children. Lhamo's family lived

in the middle of their village. To enter the high walls of the courtyard of their house, the plants and the spaciousness gave a feeling of coming into a separate world. The household consisted of the grandparents and their two daughters, including the daughters' families. Lhamo's mother was one of the daughters. Lhamo was a six-year-old girl who had cerebral palsy. She was able to walk using her hands for balance. Food was given to her in small portions which she was just able to hold with her hands and bring to her mouth. She used her whole body for communication and she appeared quite outgoing and interactive. Both her parents were teachers. The father lived in another province, coming home only twice a year. The mother taught in a small village up the road, where she lived during the week on the school campus. The 64-year-old grandmother cared for Lhamo every day by helping her dress, eat, and play. Lhamo had a three-year-old sister who lived with her mother during the week. There was another child living in the house, who was Lhamo's cousin. Compared with local standards, there were lots of things in the house and in the courtyard. Nutritious food sat on the shelves and table, as well as numerous eating bowls and cooking pots.

Separate analysis of the two families

In a first step of the analysis each family's data set was pictured as a diagram. Their recurring key expressions were captured and gave a first overall impression of each family's situation and experiences (Figures 1 and 2).

This first overview of the two families revealed their dissimilar outlook on the world and how they themselves experienced their situations differently.

Common themes and sub-themes

The analysis of the whole data set focused on the identification of patterns and relationships in both families in order to unlock common themes and sub-themes presented in Table I.

The whole data set revealed common themes and sub-themes in both families. The sub-themes are presented for each family separately, whereas commonalities and differences are kept in their original tones and expressions.

Families' views on disability and care provision: "What we have, we are willing to give"

Both of the families talked in detail about the birth experience and the time around birth. Analysis

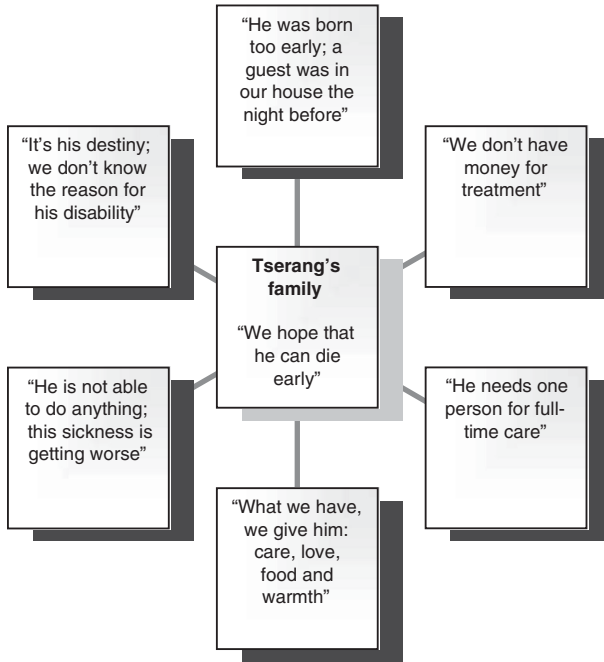


Figure 1. Tserang's family's key expressions on their situation.

showed the families' focus on times and locations of important incidents. It became clear that they trusted the local medical system, as well as the lamas as the preceptors of their Buddhist faith. Besides several medical treatments, analysis emphasized their willingness to give everything they have as well as the importance of good food.

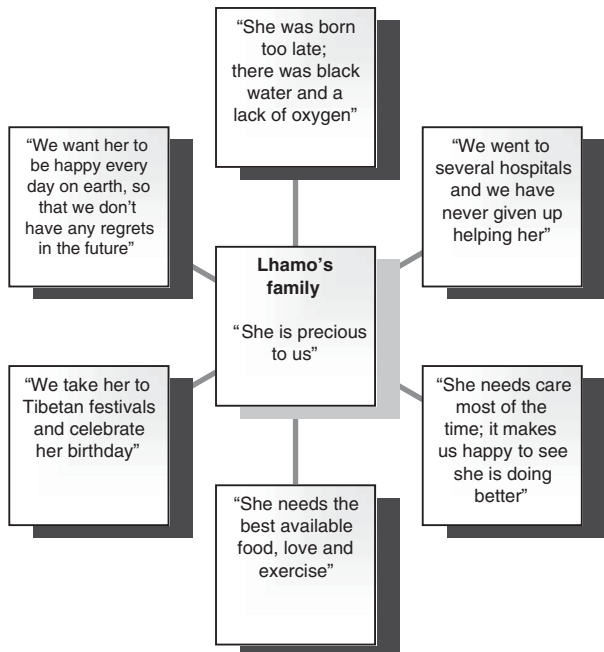


Figure 2. Lhamo's family's key expressions on their situation.

Table I. Both families' common themes and sub-themes.

Themes	Sub-theme
Families' views on disability and care provision: "What we have, we are willing to give"	Birth: Where the "problem" starts Treatments: Medicine and lama Everyday: Good food is most important
Families' occupational pressures: "One person needs to be the caregiver all the time"	Work: One worker less Caregiver: Fully occupied Siblings: "We have a different life"
Families' desires: "That the child can feed and go to the toilet independently"	Daily life activities: Needs help all the time Participation: Different from the others Hopes: Independence in daily life

Birth: Where the "problem" starts. "Tserang was born early—he stayed only eight months in the mother's womb", everybody in the family remembered. Beginning with the time before Tserang was born, the family told about a visitor in their house who brought bad influence into the house the evening before the boy was born. "Maybe that was the cause for the boy coming out earlier", several family members guessed.

"Lhamo's mother did not have an appetite during pregnancy and she was always throwing up", the family remembered. "Maybe there was a lack of nutrition and the fact that the child stayed ten months in the mother's womb might have been the cause of the illness", the grandmother and the sister reasoned. "When the baby was born the water was black because it was infected. The baby had a lack of oxygen, was weak and did not cry," they said.

Treatments: Medicine and lama. Tserang's family describe the onset of his illness when he was about five months old. The family took him with them when they went to work in the fields and let him sleep under a willow tree close by a small river. "While there, the boy fainted under the willow tree, when it was noon, he suddenly woke up and had a hard time breathing, and then he started having a fever", his father remembered and continued, "then I pressed him under his nose⁹ and he became better". The family went on: "After three days he had a fever,¹⁰ and then we brought him to the village clinic." The medicine they received from the village doctor "did not work", they said. His fever came and went, so the family sought help in the prefecture hospital, where Tserang received some medicine. From the age of one to four years old he could speak, walk, play, and eat, as the parents remembered. "We went to see Chinese and Tibetan doctors; we also went to a lot of temples". "When Tserang was seven years old, he suddenly screamed and fainted, white spit came out of his

mouth and his body became stiff—then he lost his speech ability. Since that time his condition got worse and worse”, the family remembered.

Lhamo was one month old when she started to cry. “There was some noise coming from her throat”, her grandmother described and continued: “When she was two months old something was wrong with her, her head was always bent back and she cried a lot. At the age of three months the family realized that Lhamo was different from other children. “We went to all the temples in the area and even to some in the neighbouring province. Some monks came to our house to chant”, the grandmother remembered. The girl’s situation got worse until she was eight months old, when the family took her to the hospital several times and no doctor could tell them what was “wrong” with her. “When we realized that Lhamo had this illness, we put beans inside the pillow, this helps the blood flow.” Then the family took her to a private clinic, where she was diagnosed with a stroke and encouraged to go to a hospital in the provincial capital. “When Lhamo was eight months old, the symptoms revealed that she had cerebral palsy”, the family continued, “a three-month treatment in the children’s hospital followed and a CT scan showed some water in her brain”. Lhamo received massage treatments which the family members were introduced to and taught to do themselves. When she was more than two years old Lhamo started to crawl—her grandmother said that she cried when she saw that. The family bought medicine and injections and continued the treatment in the provincial capital every month for seven days. Additionally, Lhamo received regular acupuncture treatment in the prefecture hospital as the family searched for help in several other hospitals.

Everyday: Good food is most important. “What we have, we give to him, especially care and love”, the parents said when they were asked what they themselves think is important for Tserang. Then they continued: “We give him the best to eat, we give him nutritious food, and this is the parents’ responsibility.” Then they added: “We give him good clothes to wear and a warm bed to sleep in.” When the parents were asked what they think would help the boy best, they said they would wish to take Tserang to a big hospital and try to give him acupuncture treatment.

Lhamo’s grandmother and her mother said independently: “Food, exercise, massage and acupuncture are important treatments for her.” Different family members confirmed that “Good food is most important for her”, and narrated from their experience: “If she eats well, she feels happy; this makes her cooperate better. Then secondly, exercise is

important as well. We never gave up helping her to recover and always give her a lot of different exercises.” Her mother shared openly: “I love both of my daughters, but I treat them differently because one is normal the other abnormal, the abnormal one needs more love, care, and help, not only our love but also other people’s love. Whatever we have we are willing to give to her . . . so that she can grow up healthy”, was the family’s conviction and hope at the same time.

Families’ occupational pressures: “One person needs to be the caregiver all the time”

In both situations one person was needed to provide care day and night. This was a pressure for the families since the caregiver was fully occupied and the household is reduced to a workforce of one. The data showed that Tserang’s and Lhamo’s life was quite separate and different from the life of their brothers and sisters.

Work: One worker less. Tserang’s parents explained concerning their work situation that because Tserang needs full-time care, their household was reduced to a workforce of one. “It is a lot of pressure for the family to take care of him—we need to work”, said the parents. When they went to work in the fields, either the father stayed with Tserang or the boy stayed home alone. The father, who had heart disease, took care of him most of the time, while the mother went out to work. Several times the family said that they feel sorry that they cannot afford better treatment for the boy.

Since both of Lhamo’s parents were at work during the week, the grandmother took care of Lhamo and did not work in the fields any more. The family were able to provide all the treatment available in the area. “We put a lot of effort into helping her and spent a lot of time and money for her—we tried everything we could.”

Caregiver: Fully occupied. “We need to take care of Tserang like a small baby”, the parents said and continued, “We feel sad about him, especially when we see normal children. We don’t have high expectations for him, it is important that Tserang has enough food and clothes.”

“Lhamo is different, we need to take care of everything, and we spend most of the time taking care of her”, the grandmother said and continued, “she is very precious to the family—she needs good nutrition”. After several visits, the grandmother talked more openly: “Since taking care of her, I cannot go to

some of the temple festivals any more. I feed her first every meal—I have not eaten a warm meal since. During the night she needs to go to the toilet—I have not really slept well since.”

Siblings: “We have a different life”. The older of Tserang’s two younger brothers went to school and the younger to kindergarten. From observations it can be said both of them did not help with Tserang’s day care and did not interact or play with him. The mother confirmed: “They are too young to do that.” The first brother’s daily life consisted of the following: He got up, ate breakfast, went to school, did homework, and played with other kids. The youngest one got up, played, and ate. The mother took him to work. The parents said that they do not need to worry about the two younger boys. Only the parents could take care of Tserang—the brothers were sometimes cared for by relatives. The parents said: “Sometimes relatives don’t like to come to Tserang’s house, because of his ‘situation’.”

Lhamo’s mother gave birth to a second child and explained: “When I had my second child I was glad it was a girl. When she grows up she can help her older sister a lot, especially things like going to the toilet.” Lhamo’s sister lived with her mother during the week. At the weekend they were with the rest of the family and her sister played with Lhamo sometimes, hugged her, and shared a bed with her most nights. Different family members said: “We do not say anything bad about the girl in front of her parents, we don’t want the parents to be sad—even the children do not dare to make fun of her—everybody helps Lhamo.” The grandmother added: “The other children in the house do not have milk to drink every day; they don’t get the best food.”

Families’ desires: “That the child can feed and go to the toilet independently”

As a third theme the analysis revealed the families desire to see their children living as much as possible, independently in their basic daily life activities. In their expectations about their situation, both families’ main concern was seeing their child eating and going to the toilet independently.

Daily life activities: Needs help all the time. On a normal day the parents helped Tserang get up, dressed him, fed him three times a day, and moved him to the yard. For daily care, the parents washed the boy’s face and spooned up milk mixed with bread out of a bowl. In the evening they helped him go to bed. “Mornings and evenings are more difficult”, the parents said, “we

need to put on and take off his clothes, at noon time we only need to feed him”. During the daytime, Tserang sat or lay on a piece of foam in the courtyard of the family’s house. On most of the visits, the research team found the parents (working) outside their house, and the boy was behind a locked door, home alone. Over the time span of two months Tserang had several bruises, fluid came out of his ear, and a burning wound was noted on his hand that did not heal.

Lhamo’s first activity in the morning was to eat an apple. “She eats two apples every morning”, her grandmother said. After eating breakfast, her grandmother gave her a basin with water and soap—Lhamo washed her face and hands herself, afterwards she put lotion on her skin. Then the girl moved around in the house. She had a playroom—and from observation as well as from experience it can be said that she was able to include other people in her playing. At the time of the research, she could walk, ride a three-wheeled children’s bike, and “run with a limp” around the courtyard. Lhamo also climbed a ladder in the courtyard. She knew how to draw attention to herself, and expressed joy in playing and interacting. The girl always goes with the grandmother, who also took Lhamo for her walks around the temple¹¹ in front of the village. While interacting with guests, Lhamo knew some cultural manners such as how to send people off, including gestures and saying goodbye.

Participation: Different from the others. Proceeding into deeper conversation, the parents talked more openly: “The most difficult time is the winter when we have the stove on. The boy needs to have a warm temperature—this can be dangerous for him, he can burn himself—we have to be there and watch him. The summer is easier, he can wear fewer clothes and the clothes dry easily again.” Another challenge to the parents was communication: “Tserang cannot express himself”, his parents elucidated, “he gets food according to the family’s meal time—he shakes his head when he has eaten enough”. They said that Tserang could not express when he needs to go to the bathroom, so his clothes got very dirty. The family also described Tserang’s emotions: “He laughs and cries, but when he cries it seems like he is not feeling good, or he’s sad about something.” They thought that Tserang could not recognize anybody, and concluded: “Because he cannot recognize people and express himself, he does not know how to play.” During the research period there were no toys in the house and the only interaction with him was when he got food, when he was moved out to the courtyard, or within the house. Specifically asking the

parents about special events during the year where Tserang participates they said: “During the year there are no special events for Tserang—no birthday, no June festival.”¹²

The family dressed Lhamo up in Tibetan clothes and jewellery during children’s day and the Tibetan festival in lunar June, and took her to the festivals to watch. “She is happy to be there and she imitates some dances at home”, the family members and grandmother said, “we celebrate her birthday every year with all our family members and then we buy her new clothes”. The family thought these events were important for the girl. But last year they did not take Lhamo to the June festival—“because she was different from the normal kids—they laughed at her . . . and she understood people’s talking”, said the grandmother. She felt sad and Lhamo was not happy either—which is why the family hid her last year from the festival. At weekends the family invited other children to their house to play with Lhamo. Her grandfather thought it was good if she could play with other children. He said: “She learned to jump and walk from normal children”, and further explained, “the neighbours’ children come to play sometimes—but this is a challenge for Lhamo because she can’t express herself well, then she gets angry at other kids sometimes”. The family said that there were times when the other children were unwilling to come and play with her. They continued: “Neighbours look down on her sometimes, because she is not normal, even relatives do so. We only take her to very close ones.”

Hopes: Independence in daily life. The family said several times that they hoped that maybe Tserang would be able to eat and go to the toilet by himself—their biggest hope they said was “that he could eat by himself”. Another hope as well was that Tserang would walk one day and grow more. The grandfather said, “This boy is disabled and brings a lot of troubles to his family”; he said that he hoped that the boy would die early. The grandfather did not know why the boy was disabled while other children were normal. “We hope that we can find better treatment for him—maybe acupuncture could help him.” When no one else was in the house, the parents expressed their helplessness in saying that they hoped the boy would die early so that they would not have to take care of him any longer. “If he died one day, we would give him a lot of prayers”, his grandfather said, and continued, “since he has this disease, it’s his destiny”.

When Lhamo was born, the family’s hope was that she would grow up healthily and go to school, be a part of society, and have her own family—but as she grew, they, especially the mother, realized she is not a

normal child, and that she has problems with eating, walking, and going to the toilet. The family resigned themselves: “Now that she is still like this, we cannot have too high expectations; we just hope that she can live independently.”

“Maybe this came from our gods—we cannot do anything to help, all we can do is accept it”, the family said. “Because she is abnormal, we are all worried a lot—what happens if the parents die? We don’t know how long she is going to live—maybe one day she will leave us? We give her what she likes and let her do what she wants—we want her to be happy every day on earth, so that we don’t have any regrets in the future.”

Discussion and implication for practice

This research uncovered important findings regarding the culture, beliefs, the local healthcare system, relationships and roles, as well as the personal situation of two Tibetan families with children with disabilities. Although the culture in the Tibetan villages was vastly different from a Western context, it seemed that there was a common ground in all parents’ hopes and understanding about how to care for their children. Although the two families gave different impressions and several contrasts were observed, the outcome revealed the Tibetan families’ experiences and their perceived needs in caring for their child with disabilities as well as the influences on their daily lives and occupations. Key concepts of occupational therapy, such as participation and daily life activities, were addressed by both families including the families’ desire to see their child live independently. Implications for practice as well as limitations are discussed in connection with the findings.

Both Tibetan families’ views of disability and treatment were influenced by their Buddhist beliefs. The precisely narrated birth experiences probably had their roots in the families’ belief in rebirth (20,27). Since a central Buddhist teaching is that of “anatman”, which means “no fixed self”, the child is seen as an individual that is influenced, both physically and mentally, by a being that lived previously (20,27). In terms of a child who has disabilities, Buddhists believe that the condition has arisen from the karmic actions in a previous life, and that the individual is born to undertake the consequences of those actions (20,27,44).

Rural Tibetan women believe that a safe birth depends on maintaining good relationships with the spirit world (27). Tserang’s family believed that a visitor coming to their house was the cause for Tserang’s premature birth and a reason for his disability. The belief that the bad karma was brought into

the house by a guest is a very sensitive issue in practising occupational therapy in remote Tibetan villages. Teamwork and cooperation with local staff might help to build trust in a village, as well as the study of the local culture, language, and behaviours. Local behaviours are essential in order for the family to be open towards therapy and help from outside. Flexibility concerning the therapist's schedule is necessary since participation in cultural festivals has priority for the Tibetan village people. Their beliefs require that people from outside are not welcome to enter a family's house after a birth or a death.

In telling Tserang's history, different members of the family spoke precisely about locations and events happening around the child. It could be guessed that in an area where life follows sunrise and sunset, incidents are correlated to locations. In Buddhist belief, deities and spirits are associated with water and can reside in trees (27). The family said that they put Tserang to sleep under a willow tree with a small river close by. The local Tibetan nurse explained: "Maybe there is something about the spring, because in Tibetan culture they have water gods." In reaction to this reality, the family took Tserang to the village clinic as well as to the temple and visited a Living Buddha. Lamas are called to intercede on behalf of patients because they are believed to be able to negotiate adequately with spirits (27). In Tibetan medicine there is a high awareness of body fluids (45). Lhamo's family said: "When the baby came out the next day, the water was black because it was infected." To them this was a combination of an explanation and a bad sign. Occupational therapy literature describes it being common with other indigenous peoples' understandings of health to place a greater emphasis on holism that is distinct in placing a premium on the spiritual dimensions (46). Despite their remoteness there are a variety of treatments available in the Tibetan villages. Starting at the clinic of the village doctor, people often try various treatments such as Tibetan medicine, Chinese medicine, and Western medicine. These approaches are based on different world-views. However, the treatments are not free and must be paid for in advance. Nevertheless, both of the families view basic life needs as most important: "food, love, care, and exercise" are the necessities they expressed most often. The findings regarding the situation of these Tibetan families showed that in spite of their different economic situations both families shared the same deep hopes and wishes for their children. Both families expressed it thus: "What we have, we are willing to give." Here common ground between Tibetan and Western cultures is entered, as it could be supposed that most parents are willing to care for their children's basic

needs in life. This is an underlying requirement for participation in daily life.

Since Tibetan families in remote villages live under severe conditions, their existence is constantly faced with the problem of survival (25) and all family members need to work. In Tserang's family, the second finding showed that because of one parent's need to undertake full-time care of the child with disabilities, one worker in the family is bound to the child. This reduction of one worker has an influence on the family's economic possibilities and can be a reason for poverty (47). Tserang's family said they would wish to be able to give proper treatment to their son, but since the money was not there they could not afford it.

For occupational therapy practices in a resource-poor area it might be necessary to acknowledge limitations with regard to altering the situation. It may be unhealthy to respond immediately to all the needs faced. Sustainable help and holistic development require time. In going along with the local people, their potential for self-help and achievable grassroots changes can be stimulated (8).

The grandmother said she did not go to the fields any more and she was limited in her own social life. The social contacts of both families were reduced by the fact that there was less social interaction with relatives and neighbours, which could have been interpreted as the shame and helplessness of local people in relating to children with disabilities. Only close relatives had a relationship with Lhamo's family. Although there were several relatives living in the same village in Tserang's family, there was little interaction with them. The relationships within the families were different, with Tserang's brothers not interacting with him compared with Lhamo's sister sharing bed with her and playing with her whenever she was around.

In the setting of Tibetan villages, the families' withdrawal could be explained by the workload of care-giving, their Buddhist belief, and their limited medical understanding of disabilities. In doing home treatments, while building relationships and trust, occupational therapists could help to facilitate a breakthrough of the families' isolation, and bring value and medical information to families and communities.

Not only did both sets of parents express the desire for their children to live more independently but in both cases the children participated very little in village life as well as in relationships with the relatives and neighbours. Their participation could also be stimulated through information campaigns in the village (48). If the children's participation and relationship circles increased, the workload of the care-giving person might be reduced. Working in resource-

poor environments necessitates a long-term perspective, which includes community development. Allied health professionals with skills in both health education and health promotion are suited to this role (46). Cooperation with community organizations might help to ensure ongoing ownership and maintenance of programmes (46). If development strategies such as Community Based Rehabilitation (CBR), initiated by World Health Organization (WHO), International Labour Office (ILO), and United Nations Educational, Scientific and Cultural Organization (UNESCO), reached remote areas, equalization of opportunities and social inclusion for all children would be a step in the right direction (8,47). Since CBR is implemented through the combined efforts of people with disabilities, their families and community, the families could be supported and their needs would be addressed publicly and in the context of their society (8,47).

In speaking about hope and future, the parents were facing an underlying challenge. Tserang, as a firstborn, would be obliged to stay at home, to look after the parents and to continue the family lineage (30). This realization of obligation and respect towards parents is expected to dominate the child-parent relationship (30). When a child has disabilities, the parents are forced to care for their child and the child's responsibility does not become a reality.

In a society which is predominated by Tibetan Buddhism, the public temple events are the main social activities in a village (15). Local people confirmed what Baumer & Weber (14) have stated: Tibetan festivals are for every person and family to participate in. Sick persons and those with disabilities are allowed to stay at home, since they are viewed as weak and not able to take part.

The concept of playing seems to be contrary to a Buddhist understanding of life where suffering has its roots in attachment to material objectives and people (49). The ideals are non-attachment, non-desire, and material renunciation (49), which could explain the fact that toys are rare in Tibetan villages. This might have been a reason for the parents' focus on daily life activities in sharing about the needs and hopes of independence for the child. Contrary to Tserang, Lhamo had a lot of toys and knew how to interact and include other people in her play. Family members, relatives, and neighbours interacted with her. The family realized that Lhamo could learn from seeing other children moving. In Tibetan culture, all phases of life are an essential part of moral and physical development (30). In Tserang's home, the family thought his "situation" was getting worse so there was no reason for celebration. Only as an exception did the family celebrate Lhamo's

birthday. Due to local information in Tibetan culture, people normally do not celebrate their birthdays.

Both of the families' hopes were that their children would be able to live independently as much as possible. This means in Tserang's family that he would be able to feed himself and in Lhamo's family that she would be able to go to the toilet by herself. These were probably the areas the families put most of their effort into all the time and where the families could be supported most with occupational therapy. For a therapist working in remote communities such as this we can see that while initially building relationships and trust and understanding the cultural context, occupational therapists could help to relieve the families' isolation, by sharing information and knowledge about their situation from a number of perspectives. Occupational therapy, with the aim of enabling people to participate in the activities of daily life (50), can play an important role in releasing the pressure of the families' full-time care. Home visits might be an important key in building up trust with the families and facilitating activities of daily life training.

Conclusion

Within the outcome, there were some unique additions to the current debate on cultural issues in healthcare as well as to the development of occupational therapy services in remote areas and non-Western contexts.

The two Tibetan families revealed the families' situation, their views on disabilities and care, their pressures on their daily occupations and their perceived needs and desires for independence for their children. Daily life activities, the main goal of occupational therapy, were for both families of main significance. Although attitudes, beliefs, values, and behaviours were different in the Tibetan villages in many ways compared with a Western context, it seemed that there was also a common ground in all parents' hopes and desires to take care of their children. As the two families expressed their tension between "it's his destiny ..." and "we want her to live happily every day ..." it can be said that, in a context of a remote area with animistic belief systems, supporting the family in today's challenges as caregivers might be the key to entering their world. Occupational therapists who work in resource-poor areas require a proactive adaptation to the situations faced, sensibility and understanding of culture, as well as skills of reflection on their involvement. Cross-cultural teamwork might be a key for a healthy ongoing dialogue and work.

Notes

1. A preventative health survey was carried out by the NPO in the years 2003 to 2006.
2. Revised declaration from 1983.
3. The doctor was a Tibetan woman, educated in the Chinese system, fluent in written and spoken English.
4. The grandfather was also an authority in the village.
5. Due to Buddhist beliefs, outside influence can bring bad karma to a house [20].
6. Spoken and written Tibetan was not the same. The written form was mainly used to write Buddhist texts.
7. The Chinese language was their written language, since this was what most of the local people learn at school.
8. Tsampa was typical Tibetan food consisting of barley flour, butter, and tea.
9. This is a Chinese medical method: acupressure, which is quite well known among the local people in the area.
10. In Tibetan people's understanding a person has a fever if an area of the body is warm; there are no thermometers to measure body temperature. The term fever is very common and often heard.
11. Walking around the temple is part of their daily prayers in the Tibetan areas.
12. Buddhist summer festival (solstice).

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