

Mothers' experiences of caring for a child with severe brain injury in a disadvantaged community in the Cape Flats

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ABSTRACT

Health professionals have a limited understanding of the experiences of mothers caring for a child with traumatic brain injury (TBI) in a context of disadvantage. This may be due to the dearth of qualitative research on this topic in the South Africa. This phenomenological study aimed to explore and describe the lived experiences of four mothers caring for their children with severe TBI in disadvantaged communities in the Cape Flats. Their lived experiences were described in terms of lived space, lived body, lived social relationships and lived time. Two in-depth interviews were done with each of the four mothers. Interviews were transcribed verbatim and analysed inductively. The three themes which emerged from the analysis were: "personal burden of care", "living a different life with a different child" and "holding onto faith and hope". The findings highlighted that caring for a child with TBI changed the mothers' circumstances in such a way that they had no time for themselves, because caring for and worrying about their children consumed their whole day. They also experienced an increased financial burden as they resigned from their employment to care for their children fulltime. They had to change their parenting styles as the children had different needs than before the TBI. The mothers also identified many needs of their own, including the need for meaningful occupations and support. However, they remained optimistic and experienced a stronger faith in God. The findings stressed the need for intervention with these mothers to prevent a decline in their well-being.

Key words: Traumatic brain injury, Disadvantaged community, Occupation, Well-being
A definition of key words is available as Appendix A



INTRODUCTION

The researcher's clinical experience indicated that caring for a child with a severe traumatic brain injury (TBI)¹ caused many changes in the mother's life, because her daily occupations revolved around the child's needs. While comprehensive rehabilitation is provided to the children with TBI during their stay in hospital, little focus is placed on the mother and her occupational needs once the child returns home. Severe TBI is characterised by a Glasgow Coma Scale of 3 to 8 out of 15, loss of consciousness of many days to years and post traumatic amnesia of weeks to months¹. The more severe the TBI, the more severe the impact on the child's functioning and the more demands there are on the primary caregiver of the child. Occupational therapists need to have an understanding of the lived experiences of mothers with children with disabilities in order to provide intervention aimed at assisting mothers to restore lost occupations and promote their own well-being.

The study intended to answer the question: What is the lived experience of a mother caring for a child with a severe TBI in a disadvantaged community? The purpose of the study was to help occupational therapists gain a better understanding of the contexts and experiences of mothers living in disadvantaged communities while caring for a child with severe TBI. This understanding could inform occupational therapists' practice by enabling them to provide contextually relevant occupational therapy services. The aim of this study was to describe the lived experience of four mothers caring for their children with severe TBI after discharge from in-patient hospital services, in disadvantaged communities in the Cape Flats.

Objectives of the study

Luborsky and Lysack² identified four important aspects of the lived experience to be explored in a phenomenological study, namely lived space, lived body, lived time and lived social relationships and social networks. Objectives of this study were derived and adapted from these four aspects, namely to explore and describe

- ❖ the lived space of mothers who care for their children with severe TBI while living in a disadvantaged community;
- ❖ the lived body of mothers, including roles and occupational configurations;
- ❖ mothers' lived time and
- ❖ mothers' lived social relationships and social networks.

LITERATURE REVIEW

The burden of caring for a child with TBI can be measured and described in different ways. In this study the functional and life long impact and caregivers' experience of stress were investigated to describe the impact children with TBI have on their mothers' lives.

Functional and life long impact

When children sustain severe TBI, they present with emotional, cognitive, physical and/or behavioural problems which impair their functioning significantly. These impairments may last for years and could be permanent¹. Therefore when children with severe TBI are discharged home from hospital, they continue to need supervision and assistance with the type of tasks that typically developing children use to gain independence as they grow older. Parents, in most cases the mothers, become the caregivers. Tetreault, Parrot and Trahan's³ findings showed that mothers are sometimes so involved in caring for their disabled children that they stop caring properly for themselves or other family members. Neglecting their own needs contributes to their burden of care and deterioration in their well-being.

Caregivers' experience of stress

There are numerous studies, mostly from international well resourced settings, on the burden of care, stressors and needs of caregivers with children with TBI^{4,5,6,7}. Oosthuizen⁸ explored the stressors and needs of South African families with children suffering from TBI in disadvantaged communities and found that "in accordance with international literature, families of children with TBI do have a number of injury-related stressors and needs"^{8:16}. However, these participants experienced more stress and identified

more needs than participants of studies from developed countries. Highlighted were the needs for information on TBI, their children's rehabilitation and educational progress and resources including finances, counselling and day care⁸. Oosthuizen's study concurred with other studies^{7,9} which found that caregivers of children with severe TBI are more stressed than those with mild or moderate TBI⁸. Rivara, et al⁴ reported on the Family Adjustment and Adaptation Response model, as described by McCubbin and Patterson. According to this model "the ability of a family to adapt to stress depends on the relative balance between the stressors and strains ('demands') experienced by the family on the one hand and the resources and coping strengths ('capabilities') on the other"^{4:907}. If a family struggles to cope with life stressors, the additional care of a child with severe TBI may strain their ability to cope with the added stress of the child's cognitive and physical impairment.

METHOD

Study design

Carpenter and Suto¹⁰ proposed that qualitative research allows participants to express their needs, feelings and priorities and this should lead to the development of appropriate rehabilitation services; the goal of which is to improve quality of life. A qualitative methodology was selected for this study as it seeks to understand what certain experiences are like for people, to understand and describe their contexts and to learn from their subjective experience and the meaning they develop from those experiences^{10,11}. Moustakas's¹² empirical phenomenological approach was used. This explores people's lived experiences and describes them in detail to provide a foundation for the researcher to analyse these experiences reflectively.

Study Sample

Children with TBI and their families accessing public health services in Cape Town mostly come from politically and socio-economically disadvantaged communities. Children up to and including the age of twelve years are treated in paediatric wards. The inclusion criteria for the mothers in this study were established through examining the population of mothers with children with TBI most frequently seen by the researcher ie:

- ❖ Mothers of children who were
 - between three and twelve years of age, with severe TBI and needing physical assistance and/or supervision with activities of daily living due to behavioural, cognitive and/or physical deficits.
 - discharged home between one and three years prior to the study.
 - whose total family unit's monthly income was less than R4200.
- ❖ Mothers who
 - lived with their children in a disadvantaged community¹³ in the Cape Flats.
 - were able to communicate in English or Afrikaans.
- ❖ The TBI had to be the result of a motor vehicle accident (MVA). According to Levin¹⁴ the cause of TBI in South African children is due to an MVA. She concluded that where children are involved in an MVA as pedestrians, they appear to sustain more severe TBI than through other types of MVAs. In Christ's¹⁵ study on the demographic profile of pediatric TBI in Cape Town, he found that 66,67% of the TBI population admitted to Red Cross War Memorial Children's Hospital between April and August 2007 was due to motor vehicle accidents as pedestrians.

Mothers of children with disabilities not associated with TBI were excluded from the study.

The sample population therefore comprised the mothers of children with severe TBI resulting from MVA (as recorded in the children's medical folders) following admission to a public hospital. For the period January 2006 to January 2009 a total of 76 children with severe TBI were discharged from the public hospital. Of these 76 children, 73 (96%) had a financial hospital status of H0 or H1 according to the Uniform Patient Fee Schedule of the Department



of Health (2009). A hospital status of H0 means that the family is receiving a monthly income from social grants, e.g. a child support grant (CSG) of R250, a care dependency grant (CDG), a disability grant of R1020 each, a pension or that the family is formally unemployed. A hospital status of H1 equates to a monthly family income of less than R4200. Most of the children came from the Cape Flats and surrounding rural farming communities. Purposive sampling was used, where specific participants were chosen because the researcher knew from her interaction with them during their children's hospitalisation, that they would be able to provide rich descriptions of their experiences.

Ethical considerations

This study was approved by the Health Research Ethics Committee (HREC) at Stellenbosch University (Ref. no. N10/01/004) on 12 February 2010. Participants gave written informed consent and their participation in the study was voluntary. Pseudonyms were used to protect their and their children's identity. Participants did not receive financial reimbursement nor did they incur any expenses.

Data management and collection

During the initial telephonic contact, prospective participants were informed of the aim of the study. Four out of nine potential participants indicated an interest and gave verbal consent to participate in the study. They agreed to have the first interview conducted in their own homes and the second interview either in their homes or at the hospital. The researcher phoned each participant again 1 – 2 weeks later to make an appointment for the first interview. The participants were informed that each interview would last for approximately ninety minutes. One research assistant for each of the four participants was selected to accompany the researcher to the homes of the participants and act as observers and Xhosa interpreters, when needed. The second interview was conducted approximately one month after the first one and after the researcher had analysed the first interview. The second interview gave participants the opportunity to elaborate on information they had provided during the first interview and also gave the researcher the opportunity to probe deeper into the participants' comments. Interviews with Afrikaans speaking participants were conducted in Afrikaans. The researcher did the English translation. Interviews with Xhosa speaking participants were conducted in their second language, English. If they had difficulty expressing themselves in English they could answer in Xhosa. The research assistant did the English translation. The audiotaped interviews were transcribed verbatim and saved to a computer file.

Two semi-structured interviews were conducted and audiotaped with each one of the four participants. The opening question was: "Describe a normal day in your life. What do you do from when you wake up until you go to sleep?" (Appendix B). Biographical data, including the mother's age, marital status, number of children and their ages, number of people living in the house, level of education, employment, income, ethnic group and religion, were collected to provide a detailed description of the participants.

Bracketing and reflexivity

Husserl's concept of bracketing, as used in Moustakas¹², was used to bracket assumptions about mothers of children with TBI and their contexts. Assumptions were documented in a reflexive journal, as described by Cook¹¹. The journal consisted of a methods log for interview dates, a personal log for the researcher's thoughts and a theoretical log to keep track of data analysis.

Data analysis

Content analysis, according to Moustakas's method, as described in Creswell¹⁶, was used. This involved reading through the transcriptions a few times and marking relevant phrases of how participants experienced their mothering occupations in caring for their children with TBI. The researcher grouped these statements into sub categories, categories and themes.

Rigour and trustworthiness

Four criteria were used to ensure rigour and trustworthiness, namely credibility, transferability, dependability and confirmability.

Five methods were used to enhance credibility, namely reflexivity, triangulation with existing research, member checking, peer examination with study leaders and rephrasing questions to participants during interviews. The researcher and assistant reflected on their thoughts straight after each interview. These reflections were documented in the reflexive journal. During member checking the researcher read her analysis to the participants to confirm that it was a reliable reflection of what they said. A nominated sample was used to enhance transferability. Four methods were used to enhance dependability, namely dependability audit by documenting data and methods in a reflexive journal, a detailed description of research methods, peer examination and code-recode procedure. A confirmability audit and triangulation were used to enhance confirmability. All appointments, discussions with study leaders and observations during interviews were documented to compile the audit.

RESULTS

All four participants belonged to the Christian faith and expressed a strong belief in God and in the power of prayer. Their faith helped them carry the burden of caring for their children who needed constant supervision and/or care due to the TBI. None of the participants had completed high school and they were all unemployed. All four expressed a desire to work as a means of earning an income to supplement the social grant and to escape from the monotony of being home every day. Three of the participants' children had no visible physical impairment, but they had severe cognitive and behavioural difficulties, requiring constant supervision, care and behaviour management, as described by the participants. One child attended a special school, another was in grade R at a mainstream school and the third attended a community crèche. The fourth participant's child had severe physical and cognitive impairment and needed full time care, as observed by the researcher during the interviews.

Theme I: Personal burden of care — "Hy moet at all times in my oë wees"

Constant worry

Mothers were constantly worried about their children getting hurt again. Their children's behavioural and cognitive impairments made the mothers realise that their children were at risk of being in another MVA. The children needed constant supervision, leading to mothers keeping their children indoors in an attempt to protect them. Mothers were concerned about their children's cognitive, behavioural and physical impairments and how these impairments would affect their future. "He's supposed to do things for himself, but he can't because of the accident. He's supposed to go to crèche alone. It's very very... sometimes it's sad, because I know that I have a child who cannot do anything. It's very hurting." They felt other people didn't understand their children and the children's needs. Therefore they didn't trust anyone else to look after their children. "I need to watch him every time. So I must look around, yes. To find out where is he, who, who, who is he playing with maybe."

No time for self

As the mothers were home all day with their children, their families expected them to care for disabled or elderly family members in the house. Mothers were also expected to clean the house and do the cooking. These tasks filled their day and they had almost no time left for themselves. Due to the impairments the children needed supervision and assistance with self care tasks, leaving little time for mothers to relax and participate in meaningful occupations. "Ek kan nie nog waag om deur die dag miskien 'n slapie te gaan vat of so nie, want dan speel hulle wat wakker is te veel in my brein in, dan kan ek nie aan die slaap raak nie." Mothers didn't find satisfaction in their caregiving occupations and found it monotonous and boring. "Sometimes I'm getting bored. I'm getting bored, 'cause my friends are all working." As the children had high care demands, mothers had to give up their employment in order to take on the full time



role of caregiver. They had dreams of finding employment again, but felt it would never happen, because they needed to care for their children themselves. Three mothers also had dreams of having their own house where they wouldn't have to be responsible for extended family members' care. However due to constant financial constraints this was an impossible dream.

Daily struggles

As mothers had given up paid employment to care for their children, they were dependent on social grants or family for financial support. Never having enough money to provide for their children's material needs, was a constant source of stress. Mothers also struggled with the personal stress of blaming themselves for their children's MVA. "I can say I was also the same, because I was feeling guilty maybe. If I didn't ... if I was off the time, should've been together with him." Two mothers mentioned the lack of physical resources in their community as a struggle. They were unable to find a school suitable for their children's special needs.

Small reliefs

Small reliefs were identified as material and emotional support from family, friends and the church to the mothers. Their support made the burden of care lighter. "It's getting better. Sometimes my mother told me that I mustn't stress, I'm not alone in this situation. So it's getting better." The social grants helped a little, but were never enough to cover their monthly expenses.

Theme 2: Living a different life with a different child — "Ek het nie beplan om vir haar so groot te maak nie."

Changed parenting style

Having a child with TBI was not only a source of stress but also led to positive changes in the mothers. They re-evaluated the way they were living and raising their children. Partners had a closer relationship and improved communication with each other. They paid more attention to their children and experienced a greater sense of responsibility toward their children. "Ek het geleer ek moet beter agter my kind kyk. Ek weet nie hoe sal ek agter haar gekyk het as sy miskien nou nie in 'n ongeluk gewees het nie." However, by focusing all their energy and attention on their children, mothers started neglecting their own needs. "Ek worry nie eintlik oor myself nie."

Mothering response

Mothers became advocates for their children by explaining the reasons for their negative behaviours to people who didn't understand the long term effects of TBI. "He's got very big moods. So my friends they get tired, because maybe sometimes if they press the TV, he doesn't want it, to change it ... So I just each time tell people what, what happened. Other friends they don't know about the time he has a problem." Mothers also felt the need to be overprotective of their children in order to prevent them from being involved in another MVA. A big concern for mothers was their children's aggressive outbursts. With experience, they have learnt what triggers the outbursts and they managed their children's behaviour by removing or avoiding those triggers.

Theme 3: Holding onto faith and hope — "Bid, dis al wat gaan help. En glo."

Seeking answers

From the way the mothers spoke about their children's problems and their hopes for recovery, it appeared that they were still searching for answers from health professionals to get a clear understanding of how the TBI affected their children. Even though mothers weren't sure that their children benefited from doctors' appointments, they kept appointments as they felt they were important. "Ek gaan mos nie vir my met die afspraak nie, ek gaan mos vir haar. Ek

weet nie of dit help nie. Ek weet nie of dit help nie. Hulle, hulle doen dan niks nie. Hulle vra net vrae, maar hulle doen niks."

Remaining optimistic

All the mothers were hoping for their children to recover from the TBI and to have a successful future. "Normal school like other children. He can go to disabled school until he is ok to go to normal school." Mothers chose to be optimistic about the progress they observed in their children. They compared their children's current functioning to how they were during the acute stage after the accident and could describe definite improvements, which made them hopeful for a full recovery. "Daar's nie onsekerheid nie. Ek weet sy gaan reg praat, want sover het alles nou al reggekrom al en ek weet sy gaan. Want sy't begin mos om te kruip weer en sy't gekruip. Sy't begin om weer te loop en daar't sy geloop. Sy kon nie gepraat het nie – daar praat sy.

Trusting in God's will

All the mothers believed that things happen according to God's will. Their faith in God gave them strength to deal with their children's impairments. They also believed that God answers prayers and therefore they continued to pray for their children's recovery, even though they didn't see immediate improvement. "I don't, I just give myself hope, because I, I everything I do I pray to God and that He ... I always have hope that maybe he is getting better and better and better. That he grow up, he's so ... I, I just hope every day maybe he get a little something better, yes."

DISCUSSION

The discussion follows the framework of Luborsky and Lysack². This framework proposes that lived experience can be broken down into lived space, lived body, lived time and lived social relationships and social networks. The framework has been slightly modified to expand the concept of lived body to include the mothers' roles and occupational configurations. Lived time was included within the concept of lived body, as time is an integral part of a person's occupations and roles.

1. Lived space

Lived space was described as the context in which the mothers lived and participated in their daily occupations. The context included the physical environment, namely the mothers' homes and communities, and also the economic environment.

Living in a context of disadvantage

When their children were discharged home after the TBI mothers had to take on the caregiver role for their children who had special needs because of impairments resulting from the TBI. As care giving was a full time job, mothers had to resign from their paid employment. The social grants they received were significantly less than their paid employment, which led to significant financial difficulties. Elwan¹⁷ did a literature review to investigate the relationship between disability and poverty. She found that three types of factors can further disadvantage families already living in poverty while caring for family members with disabilities. These factors include loss of income, extra costs directly related to the disability and exclusion from services and/or occupations in the community. According to these three factors, all the mothers in this study are at risk of spiralling further down the path of poverty.

2. Lived body (including roles and occupational configurations) and lived time

Mothers described a change in their roles and occupational configurations since their children had sustained the TBI. Prior to their children's TBI these mothers were involved in paid employment and leisure occupations, including socialising with friends and going to the mall. The changes to their roles and occupations were necessitated by the care their children needed and not necessarily what the mothers would have chosen, if their circumstances had been different. Role changes included letting



go of certain roles, cutting down on other roles which they valued and adding new roles.

Experience of stress

The constant worry about their children caused mothers to feel stressed in their mothering and care giving occupations. Guerreire and McKeever¹⁸ also found that the cognitive changes in children caused significant stress for mothers. For the mothers in this study caring for their children consumed so much time, they hardly ever had time to rest. Hawley et al¹⁹ found that parents of children with TBI spend less time doing leisure activities. When the mothers in this study were able to relax, they engaged in passive activities like watching TV. Lack of sleep and feeling tired was a complaint of all mothers in this study. Therefore, when they had time to relax, catching up on sleep was their activity of choice.

Identity and occupation

The mothers in this study experienced a change in their identities due to the changes in their occupations and roles. Griffith et al defined identity as "the manner in which the person sees and describes him/herself to others"^{20:83}. Christiansen²¹ explained the close relationship between a person's occupations and identity:

Occupations are key not just to being a person, but to being a particular person, and thus creating and maintaining an identity. Occupations come together within the contexts of our relationships with others to provide us with a sense of purpose and structure in our day-to-day activities, as well as over time. When we build our identities through occupations, we provide ourselves with the contexts necessary for creating meaningful lives, and life meaning helps us to be well^{21:547}.

Griffith et al. defined meaningful occupations as "activities that are particularly enjoyed, appreciated and/or considered important by the person"^{20:83}. Mothers described their daily routines and caregiving occupations as boring and monotonous, even though they were constantly busy. Csikszentmihalyi and Csikszentmihalyi as cited in Farnworth explained that "boredom is a state where the person perceives the challenges of the occupation engaged in to be less than the skills they bring to the situation"^{22:142}. This finding relates to an assumption of occupational therapy identified by Whalley-Hammell that "engagement in occupations influences well-being"^{23:61}. For the participants in this study, their well-being has been disrupted by the discontinuation of meaningful occupations such as paid work.

Spirituality

Prayer was a tool for mothers to ask for God's provision and to find peace and acceptance of their children's disabilities. Mothers' faith helped them find a reason why their children were involved in the MVA. Despite the concerns mothers had of their children's impairment, they were optimistic about their progress. Carson²⁴ similarly reported that the mothers in her study found optimism in the progress they saw in their children. Being hopeful about the future was closely linked to mothers' faith in God.

3. Lived social relationships and social networks

Mothers in this study highlighted the meaning and value of their relationships with others and their need for support. They expressed not only a need for instrumental support, but especially emotional support in the form of validation by significant others. The presence or absence of support by significant others impacted the mothers' experience of their burden of care.

Friendships

Spending time with friends was a valued occupation and mothers' main occupation of relaxation prior to their children's MVA. After their children's hospitalisation mothers found themselves spending their time indoors and visiting their friends less often, because their children needed constant supervision and/or assistance with

self care tasks. Crowe²⁵ reported that mothers of children with disabilities participated in less socialisation activities than mothers of typically developing children.

Expectations of the family

In this study there appeared to be a cultural expectation that mothers should be the primary caregivers of their children and therefore carry the main responsibility of raising the children. Three of the children's fathers did not live with them and only visited them occasionally. Primeau²⁶ explored the division of household work, routines and child care occupations in her study on couples with young children. In families with traditional divisions of household work, she found the traditional parenting style of "maternal responsibility and paternal assistance"^{26:25} when the mother takes the main responsibility for household chores and care of the children and the father provides assistance to help the mother care for the children. Having a partner, even if they were not married and not sharing an equal division of household work and child care, was however experienced as support by the mothers in this study and made the burden of caring for a child with TBI feel lighter.

LIMITATIONS

Due to time constraints the researcher could only interview four mothers, which limited the scope of the research. The researcher found it difficult to frame the questions in a way that participants fully understood. This led to more closed-ended questions and therefore the first interviews were superficial, with participants giving short concrete answers. During the second interviews the researcher repeated questions from the first interviews and attempted to rephrase questions better and did more probing to allow participants to elaborate on their answers.

CONCLUSION

This study aimed to give health professionals a look into the daily lives of mothers, having to care for a child with severe TBI in a disadvantaged community. Their circumstances changed when their children sustained the TBI which caused them to make changes in their lives. These changes meant giving up roles and occupations and led to mothers isolating themselves while carrying the main responsibility for their children's care. A lack of meaningful occupations caused dissatisfaction in their current occupations and a decrease in their well-being. However, they found strength in their faith to cope with their children's physical, cognitive and behavioural impairments. Intervention with the mothers of children with severe TBI should focus on preventative and rehabilitative strategies, including advocating for their needs by motivating for support groups in the community and developing policies which include financial support and respite.

IMPLICATIONS FOR PRACTICE

This study highlighted the need for support and intervention with the mothers of children with TBI and not only with the children. Together with the occupational therapist, the mothers need to identify and plan how they will utilise support and resources in their communities to ensure their well-being. Intervention should continue after discharge from hospital, by referring the children and their mothers to resources within their community, e.g. Association for the Physically Disabled and community health centre therapists.

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Appendix A

DEFINITION OF TERMS

Traumatic brain injury (TBI)

"An acquired injury to the brain caused by external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgement; problem solving; sensory, perceptual and motor abilities; psychosocial behaviour; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma"^{1:40}.

Disadvantaged community

"...context characterised by general adversity marked by violence and crime, a lack of adequate housing, poverty, an absence of health services, unemployment, and a lack of educational opportunities and recreational facilities"^{13:392}. For the purpose of this study, disadvantaged will also be seen as having a total family unit income of less than R4200 per month, according to the Uniform Patient Fee Schedule of the Department of Health (2009).

Occupation

"Engagement in activities, tasks, and roles for the purpose of productive pursuit, maintaining one's self in the environment, and for purposes of relaxation, entertainment, creativity, and celebration; activities in which people are engaged to support their roles."^{26:548}

Well-being

"Well-being refers to a state of overall contentment with one's physical/mental health, self-esteem, sense of belonging, personal and economic security, and opportunities for self-determination and meaningful occupation."^{22:23}

Appendix B

INTERVIEW SCHEDULE

1. Describe to me a normal day in your life. What do you do from when you wake up until you go to sleep?
2. Tell me what your life is like since you brought your child home from hospital.
3. How is your life different now to what it was before the accident?
4. What are the things in your life that make you happy and that you are satisfied with?
5. What are the things in your life that you are not satisfied with and that you would like to change?

