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Disability, Identity and Impact of Impairments on The Survivors of Road Traffic Injuries (RTIs)

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ABSTRACT

This paper examines the direct and vicarious impact of impairments on the lives of survivors of road traffic injuries (RTIs) and their families. Although the focus of analysis is at individual and household levels, in discussion it relates to social structures. Drawing on data from in-depth interviews and participant observation among survivors, caregivers and community leaders, this paper aims to provide a deeper understanding of disability and to critique ideas linked to lay aetiologies of RTIs, such as fate and individual irresponsibility. Before injury, survivors were living without disability and actively participating in their social world. The paper shows that after injury, survivors social and economic lives were altered, as they coped with changes in bodily functions, and physical capability, and in consequence, as they faced limited opportunities to engage in the social world. It investigates how types of disability affect people in different ways, in an effort to understand the links between their varied experiences, age, gender and ethnicity.

Keywords: road traffic injuries; impact; disability; identity; coping

INTRODUCTION

This paper documents the impact of RTIs on survivors and their family members including survivors' experiences of living with altered bodily functions and gender roles. It informs by many philosophical frameworks including symbolic interactionism (Mead, 1934; Blumer, 1962); the phenomenological insights of Merleau-Ponty (1962, 2002); and constructionism (Turner, 1992; Shilling, 1993, 2003). In other words, these theoretical perspectives influenced a range of aspects such as how the fieldwork was conducted in the study setting (i.e. Kuching and Kota Samarahan) and the analysis of data. Participants' diverse background such as the types of injury, age, gender, ethnicity, and education level contributed to deeper understanding of their experiences living with disability in developing country—Malaysia.

The paper focuses on survivors living with spinal cord injury (SCI), amputees and people with limbs paralysis. These survivors were important in part because before the injury they were able-bodied[1] but following RTIs they face dramatic loss of body functions. Furthermore, by concentrating on people with 'visible' disability the paper tries to tease out the complexity surround injured bodies such as the impact of disability on identity and living with limited financial support.

RESEARCH METHODS

This study used qualitative research methods such as participant observation and in-depth interviews as the main methods of data collection. Ethics clearance was granted by Monash University Human Research Ethics Committee (MUHREC) and research permit was granted by the Economic Planning Unit, Putrajaya and the State Planning Unit, Kuching. Participation in the study was voluntarily and prior consent forms were obtained from participants. Although the interviews were planned to take 60-90 minutes but during the actual interviews, breaks took place based on the needs of participants.

The analysis of data for the research involved several steps – classification of administrative data, statistics and newspaper discourses according to categories; organization of raw data according to groups such as the field notes, note expansions and audio-recorded interviews; and transcription of the audio-recorded interviews. As discussed by Hansen (2020), data collection and data analysis are often performed concurrently in qualitative research. Concurrent data collection and analysis was useful because it helped to identify the strengths and weakness of the research methods, assisted in addressing research weakness, and contribute in decision making and justification whether data collected were enough. Triangulation in data analysis—content analysis and thematic analysis was used. The combination of analytic approaches allowed researchers to draw the best from each approach and to develop a fuller, more complex picture of the phenomena investigated (Hansen, 2020). Triangulation in data analysis included comparing the data from participant observations with the data from interviews. Following Hansen (2020), in content analysis, the author emphasized the usage of words and phrases and this enabled her to focus on what was commonly mentioned by participants in dealing with their social world.

Analysing text involved several tasks such as "discovering themes and subthemes, winnowing themes to a manageable few (i.e. deciding which themes are important in a particular project), building hierarchies of themes or a code book, and linking themes into theoretical models" (Ryan & Bernard, 2003: 85). Thematic analysis is used to identify themes emerging from the data. Coding techniques were used to assist in identifying significant sections in the data. During coding sections in the data were identified, coded (marked) and then sorted into groups of like and unlike, main and subsidiary themes (Hansen, 2020). Microsoft Excel was used to summarize the participants' demographic backgrounds in terms of their age, sex, ethnicity, religion and education and data were interpreted. The majority of the participants were male: both the survivors and community leaders were male. In terms of ethnicity the majority of the survivors were Malay, reflecting that Malays were more likely to register with relevant government agencies partly because many lived in Kuching and Kota Samarahan. The majority of the participants were married and had received formal education (refer Tables 1, 2 and 3).

TABLE 1: *Demographic profile of survivors*

	Age	Years living with disability	Ethnicity	Religion	Educational level	Marital status at the time of		Occupation at the time of	
						Injury	Interview	Injury	Interview
Jalil	29	4	Malay	Islam	Primary 6	Married	Married	Sawmill worker	Unemployed
Alam	28	4	Malay	Islam	Primary 6	Single	Single	Factory worker	Unemployed
Junid	31	4	Malay	Islam	Secondary (Form 5)	Single	Single	Technician	Self-employed
Balan	51	28	Bidayuh	Christianity	Secondary (Form 5)	Single	Single	Trainee teacher	Unemployed
Jawan	35	10	Iban	Christianity	Secondary (Form 5)	Married	Divorced	Technician	Self-employed
Limah	26	11	Malay	Islam	Secondary (Form 3)	Single	Single	Student	Office assistant
Duat	32	18	Iban	Christianity	Secondary (Form 2)	Single	Single	Student	Delivery assistant
Adli	30	7	Malay	Islam	Primary 6	Single	Single	Labourer	Unemployed
Safri	26	9	Malay	Islam	Secondary (Form 2)	Single	Single	Construction worker	Waiter
Bolhan	41	2	Malay	Islam	Secondary (Form 1)	Married	Married	General worker	Security staff
Halim	46	19	Malay	Islam	Secondary (Form 5)	Single	Married	Plumber	Shop assistant
Sitam	56	7	Iban	Christianity	Secondary (Form 5)	Married	Married	General worker	Security staff
Uwai	47	9	Iban	Christianity	Secondary (Form 2)	Married	Married	Assistant driver	Security staff
Diman	19	1.5	Bidayuh	Christianity	Secondary (Form 5)	Single	Single	Student	Unemployed
Liman	42	8	Bidayuh	Christianity	Secondary (Form 5)	Married	Divorced	Lab Assistant	Office assistant

TABLE 2: *Demographic profile of carers*

	Gender	Age	Cared for	Ethnicity	Religion	Educational level
Bibi	Female	28	Husband	Malay	Islam	Primary (completed)
Aminah	Female	70	Son	Malay	Islam	No formal education
Kamal	Male	63	Son	Malay	Islam	Secondary (Form Three)
Nur	Female	50	Son	Malay	Islam	Primary (not completed)
Dewi	Female	39	Brother	Malay	Islam	Primary (not completed)
Dayang	Female	55	Son	Malay	Islam	No formal education
Siti	Female	34	Husband	Bidayuh	Islam	Primary (not completed)
Diana	Female	38	Husband	Malay	Islam	Primary (not completed)
Annie	Female	42	Son	Bidayuh	Christianity	Secondary (Form Three)

TABLE 3: Demographic profile of community leaders

	Gender	Age	Ethnicity	Religion	Educational level
Rantai	Male	56	Iban	Christianity	Secondary
Bundak	Male	55	Iban	Christianity	Secondary
Rentap	Male	64	Iban	Christianity	Secondary
Sukeri	Male	52	Malay	Islam	Primary
Ahmad	Male	69	Malay	Islam	Primary
Dollah	Male	64	Malay	Islam	No formal education
Rahman	Male	69	Malay	Islam	No formal education
Maliki	Male	64	Malay	Islam	Primary
Tahir	Male	53	Malay	Islam	Primary
Badrul	Male	65	Malay	Islam	Primary
Tinggi	Male	57	Iban	Christianity	Secondary
Chong	Male	54	Chinese	None	Primary
Mansor	Male	60	Malay	Islam	Primary
Begek	Male	74	Bidayuh	Christianity	Tertiary (diploma)
Jambu	Male	66	Bidayuh	Christianity	Secondary
Tamin	Male	71	Iban	Christianity	Tertiary
Hasnah	Female	61	Malay	Islam	Secondary
Karim	Male	63	Malay	Islam	Tertiary (diploma)
Badrul	Male	60	Malay	Islam	Tertiary (diploma)

In sum, we have demonstrated important aspects related to qualitative research and outlined how the research was conducted and why certain methods were chosen. We proceed with the findings of the study. Firstly, it considers how survivors were physically affected by traffic accidents, and how this impacted on attitudes and emotions, capacity to work and employment, and their social lives.

FINDINGS

Altered bodily functions

All "born perfect" *(dilahirkan sempurna)* survivors experienced loss of bodily functions due to injuries, and this led to restrictions in their participation in both domestic and public spheres. People who survived SCI experienced a profound impact on function, and became dependent on their families for survival. Survivors of SCI and people who have undergone amputation have to learn to live with "visible ruptures" as they attempt to gain at least some autonomy (Manderson, 2011: 93). Papadimitriou (2008: 293) states that wheelchair users have to undergo a "process of re-embodiment" – what Manderson (2011) refers to as 'rehabituation' − to come to terms with their disability; this process requires survivors to "redefine, re-examine or modify past experiences, abilities, lifestyles and habits" (Papadimitriou, 2008: 293). Several survivors in this study needed to incorporate technology (for example, wheelchairs, prostheses) into their body schema to facilitate mobility and independence. In this context, therefore, physically as well as psychologically, these survivors had to rework their identity after injuries.

Balan lost all physical capability from the neck down; as a result, he was 'totally dependent' on others for personal hygiene, feeding and his very survival. Others were 'partially dependent' on family members for daily activities, all of which they had performed without help before injury. Adli was able move around in a wheelchair and feed himself, but he was dependent on family members for other day-to-day needs, including cooking and laundry. Similarly, Junid was able to use his wheelchair inside his house but was 'partially dependent' on his family to go outside his home: "In the past, I was free. Now, I am restricted. I depend on my parents and a brother to be able to move around in my wheelchair in most places."

The desire and determination of survivors to be independent was partly thwarted by social and built environmental structures, such as access to public spaces and amenities. Jawan experienced barriers to his participation outside his home. His view about disability was in line with a 'social model': "Restricted outdoor activities occur for several reasons: no personal vehicle, public transport, such as bus and taxi services, not user-friendly, the majority of shops near housing areas not wheelchair-friendly."

The lives of survivors with less severe impairments, most with leg injuries, were also affected. Although three people were mobile with or without assistive devices, they spoke of walking more slowly and experienced mobility within and beyond their place of residence. Limah explained that she could not ride her motorcycle anymore and "moving around is slower." Diman's freedom to move around was also disrupted:

> I cannot go anywhere I like. It was so difficult for me to sit for my examination last year because it was difficult to go to the examination [on crutches]. I feel very sad. I feel sorry for myself, sad, frustrated because I cannot go anywhere. My legs are sad.

Diman's impairment and resultant disability affected him both emotionally and physically, and this was partly shaped by his I nteractions with his social world. Diman, 19 years old, knew that his injury placed him at a disadvantage with respect to securing a full-time job, establishing a career, and finding a life partner (see Henslin, 2007; Papic et. al, 2022).

People who had experienced injuries to their hands had trouble lifting heavy things and performing hard work. Hassan lost his job as a fieldworker with a surveying company after his injury, and had to look for work that did not require physical strength: "I cannot lift heavy things. Now I work as a security worker in a supermarket." Duat had to learn how to cope with his injured hand, and this took time: "Working is difficult: doing hard work and lifting stuff after the tragedy. I can't do more of it now." Although both these men were working at the time of their interviews, they received lower salaries than they had pre-accident and they had low job status. Limah and Halim, who also had injuries to their hands, experienced similar predicaments: reduced income and lower job status.

Psychological impact: attitudes and emotions

Although disability affected the lives of survivors negatively, a few survivors perceived that their injuries had transformed their lives in a positive way. Those who claimed their attitudes had changed positively portrayed creative ways of managing their disability; for example, they explained that they had become more patient and were better able to control their feelings and emotions:

> In terms of attitude, I am OK after I became disabled. Maybe I have changed a hundred per cent, to be a new person. I have learnt to be patient. (Jawan)
>
> I felt angry when my friends were teasing me, but I have to be patient. I took my desires elsewhere. The urge to see my friends is there, but I control my feelings. (Diman)

The emotional impact of disability was associated with feelings of sadness, sorrow, bitterness, discomfort and shame. These emotions are examples of the 'indirect costs' of disability, which cannot be quantified (WHO & World Bank, 2011). All participants who sustained injuries articulated that the resultant disability had affected them emotionally. However, the most significant impact was experienced by those who faced severe changes, leading to deeply 'discrediting identity' in Goffman's (1963) terms. For instance, Jawan, who survived SCI, said that he experienced "trauma, stress and depression for six years" and Adli, who lost both his legs, explained that the "effect of the accident is very bitter. It is very hard for me to face."

Diman was working on managing a discrepancy between 'self-identity' and 'social identity' (Leavey & Kelleher, 2004), a difficult task for any newly disabled person. At the time of his injury, he had had a physically active life and was a "happy-go-lucky" person. When the interview was conducted, he was a young adult and had become more mature; he reflected on "being childish," crying during his initial hospitalization.

Balan was grappling with social and psychological issues: he was quadriplegic and his dream of a career in teaching was shattered by the injury. His desire to engage in the social world failed to materialize for various reasons, including dependence for personal care and few opportunities to engage in leisure activities. He continued to feel “tormented:”

> It is very sad. Sometimes I also feel quite upset because I know I want do things but I can’t. My mind and my desire are to experience such things, but I can’t. So psychologically, it hurts; it is torturing me because I know I could do many things before injury. Now I can’t use my hands, my ability is limited.

Goffman (1963) states that stigma or ‘spoiled identity’ discredits a person’s claim to a ‘normal’ identity, producing many negative effects, including despair and shame. Consistent with this, several survivors felt sadness and shame simultaneously, in response to others’ negative attitudes and excluding behaviour; they felt the pressure or urge to participate in society and interact with others, yet were unable to do so. For example, Uwai said he felt sorry for himself because he wanted “to participate in what people do,” but he could not. Diman’s disability became the subject of teasing by his former schoolmates and classmates, and he recounted that he felt “very sad and ashamed.” Similarly, Uwai felt that he was an object of fun for others because he limped and he had to walk slower than others: “I feel embarrassed. If I walk, I am not balanced. When other persons are getting out of a car, I am still sitting, trying to get up so slowly. I cannot take a bus at all.”

Sad and uncomfortable feelings were also associated with survivors’ inability to contribute to household incomes. In Bidayuh, Iban and Malay cultures, men are expected to give money to their parents as a way of contributing to the household and as a form of appreciation for raising them. Before injury, Safri regularly gave cash to his mother and bought food items for the household. Now Safri’s family wanted him “to save the money,” to be used in the future, for example, to cover costs of transport to go to medical centre, to cover the costs of future medical care, and to pay for a new prosthetic leg when required. But Safri was self-conscious of this change in expectation: “Since the injury, I can’t help my family financially, and this makes me sad. I am sad. They don’t expect a contribution from me. They don’t want to receive my money. They want me to save the money I earned. I feel uncomfortable.”

Education and employment

Prior to injury, four participants − Balan, Limah, Duat and Diman − were pursuing formal education: Balan was in college studying for a diploma; Limah, Duat and Diman were in secondary school. After injury, Balan, Limah and Duat all stopped studying. Diman experienced difficulties in continuing his education because his injury occurred several months before the public examination, the Malaysia Certificate of Education. He missed classes and had limited time for study because he needed medical treatment and rehabilitation. His examination results were disappointing, leading him to imagine his future as one of uncertainty: “I see my future as bleak because I have a disability and my leg is impaired.”

A growing body of research illustrates the interplay between disability and poverty (WHO & World Bank, 2011) and this study demonstrates this link. As Jawan reiterated, “most persons with spinal cord injury are poor.” The majority of wheelchair users with SCI or amputations, living in Kuching, were grappling with barriers to access and opportunities, including lack of financial support and few job opportunities, given their lack of physical strength expected of manual workers.

In Malaysia people with disabilities usually occupy low status jobs and earn less income than non-disabled people (Department of Statistics, 2019). Similarly, ten survivors of RTIs in this study who returned to work after injury experienced changes in terms of the nature of their work and the place where they worked, and as a result, they earned significantly less income than they had previously. Safri explained that, in the past, he had earned each month "approximately 900 Ringgit" [US$300], but at the time of the study he received "around 350 Ringgit" [US$117] per month. Similarly, Uwai was concerned about finance:

> About money, about money to pay for many things, I am desperately seeking extra money. Before I became disabled, I could pay for stuff I needed. After injury, I worked as a security worker at someone's house for little pay. Then, my salary was increased. I cannot walk around too long. I sit during working hours.

The majority of survivors had quit their jobs after injury, and their unemployment affected their social status and their capacity to meet their daily needs. According to Oh (2021), it is difficult for those who lack a regular income to live in any society where people perceive spending power as equating with social status. Adli explained that it was difficult for him "to buy medicine and stuff" that he needed because he was not working. Jalil and his family lacked money to buy even basic food items: "After the accident, it's so hard. Working is hard. Looking for money is hard."

Altered gender roles

Gender roles may be defined as "socially shaped and shared expectations about which activities, attributes, behaviours and spheres of action are suited for men and women" (Matthewman, West-Newman, & Curtis, 2007: 433). Survivors' experiences of living with impairments and disability had shaped their views on their gender roles, identity and wellbeing.

In Malay, Iban and Bidayuh cultures, women perform the majority of household chores, although this includes physically demanding work like fetching firewood and water; men carry out most paid and unpaid work outside the home. In this study, five men were staying at home after they became disabled, which impacted their roles as breadwinners and their self-image as men, for example, being independent. Alam recounted that in the past, he "hardly [ever] stayed at home" due to work commitments, but after injury he was "always at home." Jalil explained that his spirit to work was still alive, but his injury restricted his activities: "If possible, I want to work independently. For example, I plant flowers and chillies, I do light work. I feel the impact is obvious. However, my spirit is there. My spirit, work spirit is there, but it is a bit difficult now."

As already acknowledged men are expected to provide income for their households whether they are working near home or further away. Duat said that after he received his salary, he sent money to his mother and this made her happy. She was dependent on him and he spoke of feeling obligated to help her. Despite receiving a small wage each month after his injury, Duat continued to play the role of a 'good' son by being thrifty and postponing his plan to buy a car until he had enough savings. At the time of the study, although he had lost one hand, he spent his weekends sourcing food by collecting jungle produce and fishing.

Several married survivors faced difficulties in being able to work, and their wives had to work outside the home to provide for the family. Uwai's income from being a security guard was not sufficient to support his family, and as a result, his wife had to work "extra hours to earn extra income" for the family and to pay for most of the things they needed.

The prevailing cultural images of men as independent contrasted sharply with the experiences of survivors who were dependent on families or formal carers. For example, Balan had to negotiate his identity as he was "totally dependent" on male care workers for his day-to-day needs: "I see that I have become a new person because all the things I could do before, I cannot do now. I am very dependent on others. I am totally dependent on male staff."

Some survivors were also affected because of the difficulties of doing things that they had taken for granted prior to injury. For instance, Jawan referred to "so many obstacles in our daily lives," including social interactions and leisure activities. As Limah had no washing machine, she spoke of the practical difficulties that arose when washing clothes with her hands; this task placed tremendous pressure on her time and energy.

Effects on relationships

Disability influenced the lives of survivors who were married before injury, whether the marriages ended or remained intact. Both Liman and Jawan divorced two and five years after their injuries respectively, for a range of reasons including financial difficulties and arguments about money. Subsequently, living alone, they experienced great loneliness, as Jawan explained: he was a "lonely aging man − time runs so slowly and [life] is full of boredom." Liman recounted times of sickness as his most dreaded moments. In contrast, married survivors claimed that disability had not changed the relationship between themselves and their wives, and most survivors' marriages continued after injury. Both Hassan and Jalil explained that their relationships with their wives remained unchanged, and their wives spoke of their love for their spouse as the glue of their marriage. In Bibi's (Jalil's wife') words, "love" *(sayang)* had influenced her to ignore peoples' suggestions that she leave her husband because of his severe disability.

Disabled people's relationships with their families included face-to-face interactions and long-distant relationships, mediated by visits, phones calls and short messages. After injury, family relationships were experienced in various ways, therefore: as unchanged, negatively altered or reconfigures, or closer. A few survivors perceived that disability had not changed the relationships between themselves and their families or relatives. Uwai explained that his relationship with his family members, close friends and fellow villagers "remained good after the accident" and Duat maintained a "good relationship" with his family by returning to his village as often as he could after he became disabled. Others viewed family relationships as altered. For example, Junid's relationships with his siblings had changed after injury, as a result of their attitudes and actions toward him: "They have become cold. Maybe, maybe, they are a bit reluctant to help me." Junid's tone was low and he looked uncomfortable when he recounted his experiences dealing with his siblings.

A few survivors recounted that their family relationships had strengthened after injury. Limah's experience of living with a disability contributed to a better relationship with her family:

“The relationship gets closer with family members. They love me more. I keep in touch with them via SMS, sometimes my brother calls. I always call home. Sometimes my sister calls me regarding my mother. My mother is not well now.” Limah explained that before her injury she was ‘naughty’ *(nakal),* for example, she ignored her parents’ advice and always rode her motorcycle very fast. Her family enjoyed each other’s company at home but she often missed family activities because she spent significant time outside home with her friends. Since her injury, Limah has spent most of her time at home and this has improved family relationships. Although she was working in Samarahan at the time of the interview, away from her parents, she perceived her relationship with others in the family to be closer and more meaningful than in the past.

Survivors’ friends included people they knew before injury, including classmates, schoolmates, teammates and co-workers. After injury, survivors described various situations: being friendless; having friendships unchanged; having more friends; and having fewer friends. A few survivors had no friends or romantic relationships after injury. This contradicts the idea that social bonds exist ‘naturally’ between people “based on shared location, kinship, occupation or interests” (Matthewman et al., 2007: 428). For example, Uwai explained that his friendships had ‘died’ after he acquired his impairment and resultant disability, and that his present social life revolved around his work, his family and his relatives: “After the accident, I have had no friends.” Uwai explained that both his impairment and his long working hours prevented him from mingling with his former soccer-enthusiast friends, and although occasionally he watched people playing soccer in his neighbourhood, he felt he was no longer part of the group.

Milligan and Neufeldt (2001) highlighted that people with disabilities are sexually disenfranchised by a society that inaccurately perceives them as ‘asexual beings’; as a result, they may be denied opportunities to establish meaningful relationships. In this study, no one who was single or divorced had established a special relationship with someone of the opposite sex, although a few never-married survivors spoke of their hope of having a partner or getting married so that their lives would not be lonely. For example, Duat said, “I hope to get married if someone will accept me,” but his expression implied that he believed that his impairment could jeopardize his chance for a romantic relationship. Adli confided that he had no hope of finding a romantic partner because of his impairment, but he spoke of his hope that Allah would provide him with a ‘beautiful woman’ *(bidadari)* when he died someday. Limah, the only female participant, felt that her impairment shaped people’s perceptions of her as being unable to be a ‘good’ wife or a competent mother, and that influenced her chance of having a family.

Alam described his interactions with his friends as being unaltered, partly because he was a shy person: “Before and after the accident, I’ve remained the same. I have few friends.” Alam viewed his friends as true friends because they continued the relationships with him via phone calls and short messages. Alam was comfortable with the use of technology (i.e. mobile phone) to interact with his friends, rather than interacting with them face-to-face; in this case, technology was a resource for social inclusion. All survivors except Balan used prepaid mobile phones to interact with other people, with the costs of using mobile phones relatively inexpensive for people in low-income groups.

In contrast with the general trend, a few survivors reported that their friends had increased in number after injury; these friends had positive attitudes towards people with disabilities and they were open-minded about relationships across gender:

> [Smiling] Many male friends, I am comfortable befriending men because they don't talk so much, they are open-minded and they have similar attitudes to me. (Limah, female)
>
> Many friends: roughly sixty persons. The relationship with family members and friends has remained unchanged. They view me as a normal person. (Safri, male)

Limah had friendships with both men and women, although she had more male than female friends, mostly people she knew prior to injury. She had been a member of her neighbourhood's motorcycle club and had been physically active in sports at her high school. After her injury, she established new relationships with people through her involvement in bowling training and competitions. Safri's friends comprised village friends, colleagues and teammates; the majority were male.

But most survivors lost friends after injury, including because of their geographical distance from friends and their lack of time and opportunity to engage in social activities. Balan's friends had declined drastically because he had limited chances to interact and "could no longer stay in the longhouse." When his hand was "OK," Hassan was involved in rowing and had "many friends," but his impairment and his work prevented him from participating in rowing and other social activities. Others explained:

> Now, my friends are limited and there are only a few left. My friends are from the same village, who I meet almost every day. Before injury, I had many friends. I keep in touch with old friends via the internet, SMS and telephone. (Junid)
>
> I have fewer friends since I became disabled. I socialize less frequently. I spend most of my time at home. I go out sometimes, but it is difficult to go out. No transport. Not like when I was 'normal.' I have one to two friends but we are not close. When I was 'normal', I had many friends. Friendship with disabled persons in the support group continues, but the relationship with them is not close. (Jawan)

Impact on leisure or recreational activities

Leisure activities refer to activities performed for pleasure. Based on data drawn from the interviews with survivors and carers, we established four categories of survivors' leisure activities: previous leisure activities abandoned; new leisure activities acquired; previous leisure activities modified; and previous leisure activities retained.

Previous leisure activities abandoned

A few survivors abandoned leisure activities after injury because the activities required mobility and physical fitness. For example, football requires people to run, jump and bend, and as a result, Junid, Uwai and Adli had to abandon this game. In the past, Junid was an avid soccer player and a fan of Chelsea Football Club. He used the football club banner to decorate a section of his shop.

Junid explained that sometimes he watched his favourite team playing football on television, but he felt upset because he could play football anymore.

Adli had also loved to play football and badminton, and again had to abandon his past activities:

> If I compare myself prior to and after the accident, of course, in the past, I had power *lah*. I could do everything: I repaired the house, mixed cement, drove the van, drove a lorry [and] carried wood, but now it is all gone. Playing football and badminton were my hobbies. After the things [legs] were gone, everything went. Everything I am interested in has gone.

New leisure activities acquired

A couple of carers explained that while survivors had had to abandon previous leisure activities, they had found new opportunities and acquired new leisure activities suited to their new capabilities.

> Before the accident, [Jalil] loved hunting, for example, hunting for birds during paddy planting season, fishing, and he was involved in many other things. Now he is restricted! He can plant chillies along the roadside. (Bibi)

> [Adli's] hobby before the accident was catching fish. Now he always plays with his mobile phone, his form of entertainment. He cannot walk. (Aminah)

Previous leisure activities modified

A few survivors modified their leisure activities. Diman used to enjoy riding his motorcycle and occasionally listened to music. After injury, he became a keen pillion rider on his friend's motorcycle and listened to loud music more often. Diman's mother said:

> When my husband and I go out, he [Diman] enjoys motorcycle riding with his friend. He has become the 'passenger' and his friend rides the motorcycle. He likes to listen to music. When he wakes up in the morning he switches on the loud speaker, song after song. Sometimes he goes to sleep too late − around one to two in the morning.

Safri, who before injury liked to fish on a boat on the river and swim in the stream, had modified his activities by sitting on a wooden platform constructed at the riverbank in his village, and he swam in a public swimming pool in Samarahan. Safri explained that the sound of birds and running water made him feel calm and happy. He also enjoyed the company of young children in his village while he was fishing, and he spoke of sharing his experiences and advising them on the importance of road safety.

New activities acquired

A few survivors acquired new hobbies after their injury. Liman spoke of his involvement in a catfish-rearing project sponsored by the Department of Agriculture, Sarawak, as his weekend activity. Liman's nephew was managing the project full-time; Liman played the role of advisor and was involved in marketing catfish to fellow villagers and colleagues. Junid was also involved in aquaculture as a new leisure activity and a source of income:

> [Junid] acquired new hobbies. Before the accident, he was 'working harder' than my other children. He sold items to his friends. After the accident, he 'worked' the hardest: he was involved in a fish-rearing project, he buys and sells items and he was involved in petty commerce, including sale of credit vouchers, mobile phones and mobile accessories. He can't be involved in selling heavy items though; it is problematic for him because his movement is limited. (Kamal)

Kamal perceived his son's involvement in leisure activities as a form of work because of the time and energy Junid gave to these activities. Kamal held the view that there was no division between work and 'hobbies' after injury, because all activities required Junid's commitment and the commitment of his family assistants.

Impact on identity

A 'medical model of disability' locates disability within a person's mind or body, and equates disability with ideas such as abnormality, pathology and disease (Nettleton, 2006). How survivors understood disability and its effect on identity varies however. Despite living with different types of physical disability, five survivors perceived their identity as normal. They rejected the relevance of impairments in the construction of their identity, and their impairments did not shape their views about their identity (Watson, 2002). Alam viewed himself as "OK, normal" before and after injury. Duat perceived his identity was 'normal' after he came to terms with his disability: "Now is normal. I have accepted it. Normal, normal! I don't think I am disabled anymore."

Seven survivors perceived that their disability had significantly changed their views about themselves, and they described their identity as "disabled." They also acknowledged that their experiences of living with a disability were complicated due to various factors, including their acceptance of labels imposed on them based on physical differences and their inability to do activities that they had been able to do prior to injury. In other words, in Goffman's (1963) terms, a 'spoiled identity' was used to differentiate people with a disability from able-bodied people. For example, Jalil did many things without difficulty prior to injury, but he now felt "inadequate"; Uwai said he had "become disabled, cannot walk steadily. In the past, I was normal, now, disabled."

Three survivors perceived that their identity included both disabled and normal elements. They reiterated that their brains were normal but their bodily functions were altered. Survivors' views were forms of resistance against 'the medical model.' For instance, Balan said: "I am paralysed. I cannot use my legs, I cannot use my arms. I still have my mind. My mind is still normal."

PHOTO 1 highlights Diman's perception of himself, visually, after he became disabled. Diman explained that he depicted that his head was bigger than the rest of his body because his "mind is sound" and his capability to think is similar that of able-bodied people. He reiterated that all his body was 'normal' except for his leg: "My disability is different because I can still think: my mind is sound. All my body is normal except my leg."

PHOTO 1: *Diman's drawing of himself after injury*

The social world also shaped the views of survivors about their identity and about ability and inability. When Limah compared herself with people with a severe physical disability, she considered herself normal, because she was independent and able to perform most of her daily activities. However, when she faced difficulty performing some activities, for example, washing clothes, she viewed herself as disabled. She added, "Persons with wheelchairs cannot ride buses. Normal people like me can take bus rides."

Families and friends varied too according to whether they viewed survivors as disabled or normal. Perceptions of identity in these contexts implied that significant others subscribed to the belief that two segments of the population inhabited their social world: disabled people and non-disabled people. Photo 2 and 3 support the idea of this stark binary classification of identity: disabled and non-disabled. This binary model of understanding identity contrasted with disabled participants' perceptions of more than two categories. The figures also reflect that physical difference were underpinned by multiple factors. Wheelchairs, for instance, were seen as symbols of restriction and stigma rather than of independence.

PHOTO 2: *Engaging in different activities; photo by the author*

PHOTO 3: *Living in two separate worlds; photo by the author*

The majority of significant others (i.e. carers and friends) perceived survivors' identity to be associated with negative attributes, for example, by the use of words or phrases with negative connotations such as 'lacking', 'not normal' and 'lack of freedom.' Several factors influenced these views including survivors' dependency on families for daily needs, their restricted mobility, inability to participate in high status economic activities, and being physically less active. These views reinforced the belief that disabled people were different from non-disabled people and that these negative attitudes could contribute to negative psychosocial consequences for survivors. Annie and Bibi, both carers, said:

> He [Diman] is lacking. Not normal like other kids. He is like a bird with broken wings. He may be able to fly but he is not as active as before. (Annie)

> I feel sad to see him [Jalil]. In the past we were free but now we are restricted. If we want to go to other places far from home, we cannot. Before, he had freedom such as when he went to work. Now he is always at home. So sad! (Bibi)

People who cared for survivors with the least severe injuries perceived the survivors' identity as normal, and explained that the impairment did not alter their views of the survivors' identity. Perceptions of survivors' identity were partly influenced by the engagement of survivors in economic activities after recovery and their ability to participate in social interactions, particularly at the workplace. Siti described her husband as normal, because "he is able to work" and Diana perceived her husband as "like other people." Their views implied that working and in other ways participating in social life, at a community level as well as at a household level, were among the most significant preconditions for being labelled as normal persons.

Significant others' views of survivors' identity as normal were also influenced by their perceptions of survivors' psychosocial wellbeing after injury. For example, Kamal and his family observed that Junid's behaviour and his identity changed as time went by. When the interview was conducted, Kamal said that Junid had shown tremendous improvement in terms of coping with his disability:

> A few months after the accident he had changed, of course, at first he changed. Sometimes he was dreaming and we felt sad looking at him. He was upset after the accident. He also did not know what had happened to him. Now, he is normal, OK. He goes to work. There are changes in terms of his movement, very slow. At first, he could not stand up, now he can 'stand up' on his wheelchair. We hope he has better sensation. He has a little sensation in his legs now. (Kamal)

There were differences between survivors' and significant others' (i.e. carers' or friends') views of survivors' identity post injuries (see Table 4). This comparison is important because what a survivor experiences is unlikely to be experienced by carers or friends. Survivors' and significant others' views were the basis of understanding identity from two different worldviews. One group of participants had similar views about survivors' identity: survivors with severe injuries (e.g. Jalil, Jawan, Adli and Uwai) perceived they were disabled and their carers or friends had similar views about them. However, other survivors and their carers had contradictory views about identity. This suggests that survivors' and carers' views were shaped by many factors, including their experiences, language usage, gender, age and types of impairment (see Holmes, 2010). For example, although Alam perceived he was normal, his mother perceived he was disabled because he was totally dependent on her for his survival. Other participants had mixed views. Balan and Diman both viewed their identity as having elements of both disabled and normal identities, and reiterated that their minds were normal although some parts of their body were disabled.

TABLE 4: *Comparison of views about survivors' identity*

	Survivor's view	Carer's or family member's view	Friend's view	Comparison of views
Jalil	Disabled	Disabled		Similar
Jawan	Disabled		Disabled	Similar
Adli	Disabled	Disabled		Similar
Safri	Normal		Normal	Similar
Duat	Normal		Normal	Similar
Sitam	Normal	Normal		Similar
Uwai	Disabled	Disabled		Similar
Alam	Normal	Disabled		Contradictory
Liman	Normal	Disabled		Contradictory
Junid	Disabled	Normal		Contradictory
Bolhan	Disabled	Normal		Contradictory
Halim	Disabled	Normal		Contradictory
Balan	Normal & disabled	Disabled		Mixed
Diman	Normal & disabled	Disabled		Mixed
Limah	Normal & disabled		Normal	Mixed

Psychological impact on children

Lack of understanding of disability and negative attitudes among members of the community affected not only survivors and their primary carers, but also other family members, as demonstrated in Bibi's family. Bibi's son was being teased by a few of his schoolmates because his father had a disability, but he subscribed to the belief that men are not supposed to cry in front of other persons. Although being female is usually associated with sensitivity, Bibi's daughter also felt unable to cry in front of 'bullies.' Bibi's children used "varied and creative ways to resist and actively counter the negative effects of stigma" of living with a disabled parent (Green, Davis, Karshmer, Marsh, & Straight, 2005: 197). Bibi explained:

> Sometimes other children tease my children because their father is disabled. One time, some children said, "How come other fathers can walk but your father can't walk?" Although my son was upset about the teasing, he kept quiet and didn't cry. When the weather is fine, we go around with the motorcycle. My children like having a ride. Other girls from the same neighbourhood also teased my daughter, and she told me about her experiences.

Bibi's husband's injury was the result of a motorcycle collision with a car. Although the traffic accident initially caused Bibi to suffer a phobia of using a motorcycle, her fear slowly eroded as time passed, and she perceived their motorcycle as a resource for inclusion, giving them freedom to move around their neighbourhood.

Halim's daughters aged sixteen and eight years old, never invited their school friends to their home, partly because they were ashamed of their dilapidated house and of being poor. However, a few of their friends from the same village were invited to their home during the festive season (i.e. Eid Festival) because they felt that these friends understood their situation. I suggest Halim's children's strategy was creative: they knew their classmates and schoolmates came from different geographical settings and socio-economic status, and some of these students had negative attitudes towards people with disabilities and poor people.

Financial hardship

Other household members also faced financial difficulties. For instance, Diman and his mother (Annie) explained that their family had been in bad financial shape since Diman's injury, because the breadwinner (Diman's father) was frequently on leave from work to take Diman for medical treatment:

> My family's financial standing is badly affected. My father is a truck driver. I go to the hospital so often and my father has to take leave to take and collect me. He gets a lot less money now. So terrible! Luckily, relatives top up some money to reduce the financial burden. (Diman)
>
> We have had financial problems, especially when Diman was initially injured, because his father didn't go to work. We used up our savings to repair the motorcycle, to buy petrol, to cover my children's school expenses. I also didn't cook [lunch]. [Diman's] siblings had to eat instant noodles. Our financial status is bad. Going to other places is difficult. (Annie)

The impact of injury on Dewi's family was also significant because of the large household, and the need of household members to support Dewi's sister who was living separately.[2] Their financial difficulty was exacerbated because Dewi's husband was often ill, and the care-recipient (Adli) received very little financial support from the government. Dewi said sadly:

> My life is hard. I have many children, but I don't contribute to help my mother' financially. My older sister doesn't understand our circumstances because she still asks our mother for money. Therefore, my brother [Adli] is very upset with his sister and the other siblings. He doesn't like his elder sister. Adli observes my family situation. Although I'm angry with him, I'm sympathetic to him. He has no other siblings who are willing to share his burden. Although I scold him, he remains with me because I feed him. I cannot stand feeling sad when I hear, "I have no money. I haven't eaten chicken for ages." (Crying) Now he's all right. If he dies one day, I can't replace him. When he was 'normal,' he didn't give money to me. Now, he always asks me for money. I have many burdens. I have children who are still at school. I care for my mother and I care for him. I have no more savings. I live a very simple life now. If I'm sick, I leave it to God. I have shared my difficulties with a few government workers, but they just kept quiet. As long as I am able to work, I work to assist my husband to feed my family. We will just eat whatever we have, eat porridge with salt.

Dewi's experience reflected the 'double life' of the family – the family was a source of conflict and dissatisfaction as well as support (Matthewman et al., 2007). At the time of the interview, the cost of living in Kuching and Samarahan was high. Chicken cost between RM7-8 (US$2.3 to US$2.7) per kilogram, and beef was RM35 (US$11.7) per kilogram. Bibi's experience was an example of how financial difficulties affected her family. She perceived chicken as a ‘luxury’ food item; her reference to “eating porridge with salt” suggests a minimal diet.

In addition, after injury, the lives of members of several families were affected because of arguments and lack of time for a break or vacation. Annie lamented that “family relationships are stressful” and plans for a holiday were cancelled:

> Sometimes I argue with my husband. I also argue with my son because he is too lazy to exercise. The most significant effect is that we cannot return to the village for Christmas. We cannot enjoy life as this family is in a state of sadness. There is no happy hour. We cannot go back to the village because he is sick. Our plan to go to Miri had to be cancelled.

Bibi’s family life was affected after Jalil’s injury because they lacked finances, and their opportunity to interact with the social world was limited, leading them to feel alienated. Although Bibi and her family were “doing family” by “always staying at home together,” her young children were bored. Bibi’s view of family life was contradicted by her husband, the care-recipient, Jalil, partly because of difference in the needs of various members of the family. Bibi’s two-year-old son loved to be carried, but Jalil could not lift him. Although Jalil felt sad that he was unable to do this, he needed understanding from his family.

Responding to disability

After injury, participants spoke of their psychological, physical, social, and spiritual responses or reactions. These responses occurred during the initial stage of their lives post injury, which may be seen as period of ‘rehabilitation.’

Psychological responses related to survivors’ abilities to cope mentally with the accident and consequent impairment and disability. This involved reflection and self-evaluation of their attitudes, which led to their increased capacity to cope mentally. The initial stage of injury was the most difficult moment for all survivors, and having a positive attitude helped some of them to cope with the drastic changes to their lives. As participants had varied forms of injuries, the duration involved in coping varied significantly. Safri, who had an amputation below the knee, said that he coped within days, while Jalil, who survived SCI, took months to cope:

> It took me more than a week to accept my reality. My attitude helped me. Feeling sad and crying will not make my leg come back. So, I accepted it. (Safri, left leg amputated)
>
> At first, I was shocked and did not accept it. After thinking about it repeatedly for a few months, I finally accepted it. (Jalil, SCI)

Coming to terms with physical impairments for some involved coping with the pain associated with their disability. People with less severe injuries experienced less severe pain, as in-patients and post-hospitalization. Those with severe impairments experienced pain after medical interventions and after returning to their communities. For example, Uwai described that he coped with physical suffering for months before he was able to return to work: “I did not work for more than a year. I endured my injury for a few months before I healed. I was hospitalized for four months. My bone was broken and it was taken out."

The social contexts of coping involved families and non-family members. During hospitalization all survivors experienced isolation while after discharge; their families were involved, providing them with emotional, spiritual and practical support. For instance, Limah avoided contact with non-family members after her injury but her family members, especially her mother, helped her to cope with her self-exclusion and lack of confidence:

> After the tragedy I interacted less with other people compared to when I was 'normal.' I was ashamed. I did not go out at all. I felt ashamed when with community members. Then, my brother invited my mother and me to visit him in Miri, to learn how to be independent. After that, I tried to think positively: there is no reason to be ashamed in front of other people because I was 'normal' before, then, I became disabled. Feeling ashamed to go out is not good. After becoming disabled, I was less confident to face the social world. I did not go out of the house. I was ashamed. Hiding from people, hiding! Now it is all right. I am involved in sport, work. I make myself happy. I create happiness and make jokes.

Limah's strategies to cope with her impairment, including overcoming her feelings of shame and initiating interactions with members of her community, despite feeling awkward initially, demonstrates that coping with a disability involved "resocialisation" − the process of learning new norms, values, attitudes and behaviours (Henslin, 2007: 85). Several survivors spoke of the involvement of both families and friends in providing emotional, physical, spiritual and social support. Junid recounted his experience of living with a disability during rehabilitation, when he was totally dependent on family members and friends, and post rehabilitation when he became capable of performing several tasks: "I manage myself well now. In the past, when nobody was around to help, I could not do anything. Now I still need help from my family, for example, to put on my clothes or go to inaccessible places."

Coming to terms with disability also involved non-family members, including the rehabilitation doctor, physiotherapist, employer and members of support groups for people with disabilities. For example, the Kuching Spinal Injury Association (KUSIA) was established in Kuching City to provide support for people living with SCI in Kuching and Samarahan. Jawan spoke of attending a seminar organized by the Department of Social Welfare in collaboration with the Sarawak Society of Disabled People, which became "the turning point" of his life, while his experience in a rehabilitation centre shaped his views of his capability. Duat also spoke of the benefits he gained from the training he attended, and Safri was grateful to his employer:

> After the accident I was very sad and I could not accept my condition. I stayed in the longhouse for three to four years. Then, I attended training in a rehabilitation centre and furthered my training in Kuala Lumpur. After that, I have worked independently. (Duat)
>
> My employer had no confidence in me at first. I proved to him that I could work. Now, he likes me. I have asked him to increase my salary. (Safri)

Safri had to demonstrate to a potential employer his capability to work by taking customers' orders and carrying food and drinks on a tray. After this demonstration, he was accepted as an employee in a coffee shop. Although younger customers sometimes scolded Safri for being slow in taking orders, they apologized after they discovered he had an amputated leg and was walking with prosthesis. Halim's employer, Mariam, said that she provided Halim with a job because she pitied him; while this attitude can have negative connotations, the Malay term lacks this valency. She treated Halim with respect, and she believed all people have dignity.

Most participants recounted their reactions to disability as 'step by step' within their capacity. Balan spoke of responding in 'chaotic' ways. Because he experienced dramatic changes functionally, the disability affected him severely and at a particular stage, he had had suicidal thoughts. Balan has since had to integrate all aspects of coping strategies, including psychological, physical, spiritual and intellectual, to manage his life:

> I refused to eat, to drink for a few months, and I became very sick, and doctors were always trying to persuade me to take something, but I refused. Towards the end, they put a tube in my nose, I was fed by tube and I discovered that I was suffering. Moreover, I talked to myself: "Oh! If this is the case, I cannot die. Even when I wanted to die, they gave me tube." So, I might as well, I said, "I try to accept it." So, from that day, I started to take action, I started to ask friends to read the Bible to me. After six months, I started to like myself; I consulted a physiotherapist, met professionals. I used my mouth to open books, so that I could read, and I read, read, and read. Therefore, I started to take advice from people, so I started to feel better. My mind changed, my attitude changed. Slowly, day by day, week by week, month by month, and then, I can accept it. Of course, I can say that I do not accept it 100%, because I do grumble when things do not go that well. I grumble.

Balan's attitudes and responses may be viewed as an extraordinary achievement. Significant numbers of people in Malaysia die within a few days or weeks of being paralysed (from infection, primarily), yet Balan was living beyond the time expected by others. Balan had shared his experiences with a range of people, including schoolchildren, medical trainees and community members, via seminars and talks, especially after he went to live in a NGO-based institution. In an interview in a local newspaper in the middle of 2010, Balan concluded that his disability had taught him "to value life," implying that his capability to face severe physical impairments was linked to wider contexts. Balan's attempts to understand what had happened to him during the initial stage of his injury involved not only medical teams, friends, family and his reason, but also, most importantly, his faith in God. Other survivors, including Jalil and Adli, spoke too of using spiritual approaches to cope with their impairments and resultant disability.

CONCLUSION

Survivors' perceptions of their social worlds were shaped by their experiences of living with their altered body, altered relationships and stigmatized identity. Long-term physical impairments and resultant disability affected the lives of survivors both directly (e.g. through loss of bodily function) and indirectly (the socio-psychological suffering survivors experienced as feelings of shame and sadness). Therefore, survivors' experiences were critically important in the context of this study. Participants in this current study who had survived traffic accidents were coping with two types of identities in their daily lives – 'personal identity' and 'public identity' (Kelly & Millward, 2004), and survivors with severe impairments appeared to deal with more challenging social worlds, including their attempts to understand the meaning of their disability, which is not explain in this paper.

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FOOT NOTES

[1] Dollah used the term to mean able-bodied people.

[2] Ideally, Dewi's sister should have supported them, but this was not the case because she was poorer than Dewi.

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